Chapter 1

'Life holds a meaning for each and every individual, and even more, it retains this meaning literally to his last breath.' (Frankl, 1970)

Breast cancer has been a focus of research for many years; however until recently the existential experiences of persons who have breast cancer has been an under-researched field. Receiving a diagnosis of cancer may reflect patients' first confrontation with their mortality and may result in an existential crisis (Fulton, 1979; Hayslip & Hansson, 2003; O'Connor, Wicker & Germino, 1990). This existential crisis may elicit a sense of suffering in the patient which may be extensive and pervasive, affecting their physical, psychological and social domains. However, patients who had experienced difficulties in life were said to be more familiar with death and thus more accepting of death (Hayslip & Hansson, 2003). This medical crisis forced patients to engage with their existential concerns however facing ones' existential concerns does not necessarily culminate in an existential crisis (Blinderman & Cherny, 2005).

According to CancerStats (2005), breast cancer is the second most diagnosed cancer in the world and its incidence is increasing worldwide. If detected early, it has a fairly good prognosis and this has led to a significant number of women surviving. Furthermore CancerStats (2005) reported that each year 10.9 million people are diagnosed with cancer and 6.7 million people die of cancer. That means that 4.2 million people experience firsthand the stressor known as a 'cancer diagnosis' and go on to live with cancer. There is immense fear attached with receiving a diagnosis of cancer which is rooted in the unknown etiology of cancer and that, even after extensive surgery; treatment and remission, death is always a possibility (Guex, 1994; Henouch & Danielson, 2009; Kübler-Ross, 1969; Richer & Ezer, 2000; Westman, Bergenmar & Anderson, 2006). In addition, this fear may be rooted in the unexpected, distressing transition from an asymptomatic wellness to facing a potentially life-threatening illness (Lally, 2010).

The quintessence of psycho-oncology is to address the "suffering of the mind" that cancer poses to its patients (Holland, 2001, p 465). Here, suffering, of the mind in particular, is defined as "a

perceived threat to the integrity of the self, both physical and psychological" (Chapman & Gavrin, 1993, p 6) and is said to foster transformation and transcendence as well as cultivate a greater appreciation for life and one's relationships (Arman & Rehnsfeldt, 2003; Frankl, 1997). The reception of this diagnosis steers patients to face the reality of their situation. They need to develop 'a will to live' with and accept that they have cancer in order to "fight for their existence" (Landmark, Strandmark & Wahl, 2001, p 223). Similarly, Frankl (1970; 1997) stated that humans are characterised by 'the search for meaning' which is an ongoing, dynamic process that occurs continuously throughout life especially when life stressors are presented. This 'search for meaning' may lead patients to find meaning in their experience, fulfil their purpose in life and achieve self-transcendence (Frankl, 1967; Frankl, 1970; Frankl, 1978). Conversely, if meaning is not attained, emotional maladjustment may result (Frankl, 1997) and despair may be experienced due to the inability to cope with their diagnosis. Despair, as defined by Frankl (1997) is the psychological suffering of a person who has not found or been able to find meaning. In order for patients to achieve self-transcendence, they must have the will to make sense of and find meaning in their particular circumstances (Frankl, 1970; Frankl, 1997). Thus in order for breast cancer patients to come to terms with their diagnosis, they must want to find and then go on to make meaning.

To achieve this state of self-transcendence, one must understand what drives the process of meaning-making of our lives. Hence, existentialism is the philosophical exploration of the human condition of making meaning of life and death, right and wrong, guilt, meaning and loneliness (Westman, Bergenmar & Anderson, 2006). Morgan (2003) reports that spirituality is a fundamental component of existentialism; thus he defines it as a person's perception and philosophy of the world and the system of meaning that they hold about the world and themselves. While there is no universal definition for existentialism, Henouch and Danielson (2009) identified several components of existential concerns, namely: sense of control; dignity; life satisfaction; hope or hopelessness; meaning; autonomy; self-esteem; being positive; loving others; relating to God; need for information and being with family. Similarly, Taylor (2003) delineated spiritual need for meaning into seven categories: a need associated with relating to an ultimate other; need for positivity; gratitude; a need for hope; need to give and receive love from other people; need to review beliefs; need to create meaning and find purpose; religious needs

and the need to prepare for death. As the conception of existentialism is so vast, this study hopes to investigate concerns regarding meaning of life, sense of control, self-esteem, being positive, being with family and relating to God and others that are common to participants.

These specific existential and spiritual needs of breast cancer patients arise when the issue of mortality triggers their existential 'angst' (Pascal & Endacott, 2010). In order for patients to overcome this, they must achieve transformation, meaning-making and transcendence in which patients gain a new sense of integrity, balance and wholeness in their life (Henouch & Danielson, 2009). Similarly, Guex (1994) stated that patients need to come to terms with their illness and health care options and obtain a carefully deliberated emotional balance and satisfactory self-image in order to retain adequate social and vocational integration by meeting their existential and spiritual needs. Westman, Bergenmar and Anderson (2006) supported this idea as they state that issues related to body changes; self-esteem; work competency; relationships; parental responsibility and one's social life are likely to be questioned, changed or even interrupted during this period. There is a need to unpack patients' existential domains in order to increase our understanding of this experience and develop interventions that improve adjustment and the quality of life for breast cancer patients. Thus, this study explores the existential concerns of breast cancer patients who had recently ended treatment in order to understand where they found the strength to fight their disease; what assisted them in their fight and their fears and hopes for the future. Henouch and Danielson (2009) as well as Richer and Ezer (2000) assert that a greater awareness of psycho-spiritual adjustment led to greater meaning-making of terminal illness which may result in an improvement in the patient's quality of life.

1.1 Rationale

Cancer is recognised as one of the most feared diseases in existence (Guex, 1994) as it introduces a profound threat to the body and mind (Arman & Rehnsfeldt, 2003). Prior to the early twentieth century, receiving a cancer diagnosis was characterised by stigma, terror and fear which led medical practitioners to withhold this diagnosis for fear that the 'mind-body relationship' would exacerbate the patient's death far sooner than medically predicted (Guex,

1994; Holland, 2001). This lack of knowledge and fear gave rise to uncertainty which seemed to consciously initiate engagement with existential concerns which may have resulted in distress within cancer patients (Guex, 1994; Henouch & Danielson, 2009; Kübler-Ross, 1969; Westman, Bergenmar & Anderson, 2006). However, due to technological and medical advances in the form of early prevention and improved treatment protocols, the survival rate of cancer patients have improved drastically (Guex, 1994). As such, more and more patients are surviving cancer and these survivors seemed to attribute their success to their psycho-spiritual adjustment and this indicates an urgent need for psychological assistance of cancer patients (Allen, Savadatti & Levy, 2009; Arman & Rehnsfeldt, 2003).

There have been several recent studies that showed that women experience distress immediately after the completion of treatment, however, there is insufficient information pointing to the source of this distress (Allen, Savadatti & Levy, 2009; Arman & Rehnsfeldt, 2003; Henouch & Danielson, 2009). Allen, Savadatti and Levy (2009) called for more research to examine the journey which patients follow from being a ‘patient’ to becoming a ‘survivor’. Similarly, Arman and Rehnsfeldt (2003) stated that there was a need for research into understanding the lived experiences and suffering of breast cancer patients. Previous studies on cancer patients focused on gathering quantitative, objective, empirical evidence. However, researchers have had the propensity to negate looking at events from an emic and subjective perspective of the cancer patient. This is especially evident in the way in which cancer patients interpreted and internalised events as well as how their perceptions were influenced by society (Ashworth, 2006; Snape & Spencer, 2003). Hence, there is a need for qualitative research in order to gain information of how breast cancer patients and survivors make meaning of their lives in order to guide and improve interventions to support psychological adjustment (Allen, Savadatti & Levy, 2009).

Studies by Allen, Savadatti and Levy, (2009); Henouch and Danielson, (2009) and Westman, Bergenmar and Anderson (2006) showed that patients who had greater psycho-social functioning and adjustment had a better quality of life. Arman and Rehnsfeldt (2003) after a meta-analysis of 14 journal articles concluded: “that breast cancer patients’ experiences might have been misinterpreted in a reductive way” (Arman & Rehnsfeldt, 2003, p 523) as they noted the lack of detail in the description of certain phases such as the ‘initial tragedy stage’; ‘suffering’ and

‘transcendence’ described by nurses and researchers. They further postulated that obtaining the patient’s view of their own suffering more accurately may reflect the needs of this population and this may alleviate interviewer bias. This study sought to collect narratives directly from breast cancer patients with particular regard to their existential concerns and experiences.

South Africa is a nation where cultural diversity is a ubiquitous feature that exists in various contextual enclaves. Lo Castro and Schlebusch (2006) stated that the relationship between stress and breast cancer had been observed to influence increased perceptions of threats which included cognitive, emotional, inter-personal, physical and socio-cultural factors. Context and culture are important factors as they affect the perceptions of cancer and resources available to cancer patients. Thus the increased perceptions of stress may have been due to lack of education, lack of early detection and seeking alternative treatments before presenting at hospitals due to socio-economic class differences (Lo Castro & Schlebusch, 2006). Thus Culver, Arena, Wimberly, Antoni and Carver (2004) stated that it is of vital importance to ascertain which existential differences were attributed to socio-economic status and which were attributed to ethnicity and culture (Culver, Arena, Wimberly, Antoni, & Carver, 2004).

The prevalence of breast cancer is increasing especially in African countries due to their increasing adoption of Western socio-cultural norms (Fregene & Newman, 2005). Currently the South African health-care system, has few key-care facilities, equipment and staff available, who are over-extended, to provide adequate medical services to the South African population. Pillay (2001) conducted a study that sought to empirically evaluate emotional factors of adults who were recently diagnosed with cancer. This study highlighted the manifestation of psychological symptoms in newly diagnosed cancer patients and emphasised the need for concerted efforts to provide appropriate psychological care to such patients. Furthermore, he stated that the psychological management of cancer patients was often ignored or superficially handled by doctors and nurses due to their primary focus on physical health (Pillay, 2001). Therefore, there is an urgent need to outline and develop community interventions that could provide social support to cancer patients in order to improve their meaning-making and coping processes, which in turn would improve their quality of life (Lee, Cohen, Laizner & Gagnon, 2006; Pillay, 2001).

In a South African study by Schlebusch and van Oers (1999), higher levels of psychological distress were reported amongst Black breast cancer patients compared to White cancer patients. The results of this study indicated that Black and White breast cancer patients experienced their disease differently and that their level of psychological distress differed markedly. This was reportedly due to the Black communities culturally diverse views of health and disease as well as the historical lack of psycho-oncological services for Black patients (Schlebusch & van Oers, 1999). Black women seemed to suppress or somatise their emotions due to traditional and cultural reasons which according to Schlebusch and van Oers (1999) account for the higher levels of psychological distress experienced by these patients.

South African community is comprised of a mixture of collectivistic and individualistic cultures in which collectivistic cultures focus on group perceptions and values while individualistic cultures generally follow the western view of life (Stead, 1996 as cited in Hook, Watts & Cockcroft, 2002). In South Africa, collectivistic cultures are prominently found in the Black, Indian and Chinese communities. In addition, these communities tend not to follow western forms of spirituality; instead collectivistic communities reflect interconnectedness amongst community members and hold beliefs in ancestors, rituals and multiple gods and spirits; these religions reflect a more spiritual component than traditional Christianity (Kruger, Lubbe & Steyn, 2008). In African communities, mental illness tends to be manifested physically and physical illness is said to be cured by traditional methods using potions and spiritual healing by *isangomas* and *inyangas* (Kruger, Lubbe & Steyn, 2008). These views are held by communities and thus also influence the communities' view of cancer and its treatment. This must be taken into account when prescribing treatment to cancer patients as their views may be different from traditional western views of illness and treatment.

Thus, the existential needs of patients from diverse non-western ethnic, religious and cultural backgrounds have been inadequately studied. Recommendations from various research studies have called for future research to explore the relationship between cultural and existential parameters (Carter, MacLeod, Brander & McPherson, 2004; Taylor, 2006). Previous studies samples were predominantly Caucasian *[sic]* women from the Americas and Europe whereas

other studies have gauged existential reflections of participants from medical staff. There seemed to be a lack of generalisability and gaps in understanding of whether these concerns are common to all breast cancer patients, therefore as the majority of studies on breast cancer had been done on westernised populations, there is a need for an African perspective. In addition, in South Africa, few researchers have contributed to the body of knowledge regarding South African views of existentialism (Lo Castro & Schlebusch, 2006; B. Pillay, 1996; A. Pillay, 2001; Schlebusch and van Oers, 1999) and thus the body of knowledge with specific reference to existential concerns of breast cancer patients and survivors in this field has not yet been comprehensively covered.

1.2 Research Aims

This study aimed to explore patient's emic, subjective views of meaning-making and to explore the cultural variations between Black and White South Africans. These aims were accomplished by exploring what South African women considered to be existential concerns in relation to how they experienced breast cancer as well as understanding how they persevered in the face of adversity; where they gained their strength from and how that helped them to make meaning of their situation.

Chapter 2: Literature Review

"One way of expressing the fluidity which is present in such existential living is to say that the self and personality emerge from experience, rather than experience being translated or twisted to fit preconceived self-structure. It means that one becomes a participant in and an observer of the ongoing process of organismic experience, rather than being in control of it." (Rogers, 1989)

When a person learns that they have breast cancer, their psychological reactions include the fear of death, disfigurement, and disability; fear of abandonment and loss of independence; fear of disruption in relationships, role functioning, and financial standings; and denial, anxiety, anger, and guilt (Saddock & Saddock, 2007). Henouch and Danielson (2009) found a strong relationship between meaning and concepts from physical, psychological and social domains indicating the pervasive nature of breast cancer. This leads one to believe that breast cancer impacts and influences every aspect of the patients' life. It was previously assumed by medical professionals that once a patient knew about their disease that would evoke feelings of distress and despair and would result in the patient giving up hope and succumbing to their illness (Guex, 1994). However, there is evidence now that cancer patients experience physical, psychological and social level concerns that lead to an existential reappraisal of their life. Receiving a diagnosis of cancer is particularly important as this prompts patients to question their purpose in life as well as engage in coping strategies such as denial, bargaining and later, facing their reality; this may lead to determination to live and ultimately to fight for one's own existence (Arman & Rehnsfeldt, 2003; Kübler-Ross 1969). Finding purpose in life and meaning in cancer are fundamental existential concerns and thus, making existential changes is the overriding theme of the lived experience of having cancer (Halldórsdótti & Hamrin, 1996). Several studies concluded that this reappraisal seemed to cultivate transformation of one's experience and initiated the will to live which manifested in a greater appreciation for life and one's relationships (Arman & Rehnsfeldt, 2003; Frankl, 1997; Kübler-Ross 1969). Several empirical studies (Allen, Savadatti & Levy, 2009; Arman & Rehnsfeldt, 2003; Carter, MacLeod, Brander & McPherson, 2004; Henouch & Danielson, 2009; Kernan & Lepore, 2009; Landmark, Strandmark & Wahl, 2004;

Saddock & Saddock, 2007; Schlebusch & van Oers, 1999; Skrzypulec, Tobor, Drosdzol & Nowosielski, 2008; Taylor, 2006; Westman, Bergenmar & Anderson, 2006) have explored the existential concerns and meaning-making processes of breast cancer patients. Thus the focus of this study is to uncover the existential concerns within the South African context.

2.1 Psychological Perspective

2.1.1 Existential Meaning and Adaptation

The common thread between the theories of existential meaning seems to be where meaning leads to transcendence which in turn leads to adaptation and adjustment. This can be interpreted as having the belief that life has meaning which individuals experience in their everyday living (Landmark, Strandmark & Wahl, 2001). The term 'belief' has been extensively used by patients to describe a fundamental element of the experience of cancer. Beliefs are defined as the essential assumptions, ideas and opinions held by individuals that are conscious and unconscious as well as rational and irrational; it is these beliefs that determine the individual's progress through life (Richer & Ezer, 2000). This leads one to believe that breast cancer impacts and influences every part of the patients' life. Wright, Watson and Bell (1996) placed 'belief' at the heart of nursing practice and illness conception, thus confirming that being diagnosed with a terminal illness often challenges or threatens one's existing systems of belief and thus may be the precipitating factor for disrupting ones ascribed meaning. This study stated that the beliefs one holds about an illness can determine how they make meaning and will cope with their illness (Wright, Watson & Bell, 1996). Beliefs can be readily elicited or described and are said to be part of one's' cognitive structures (Beck, 2005). At a conscious level, beliefs are mostly rational and concrete representations that may change abruptly with new information or after particular events such as receiving a cancer diagnosis (Richer & Ezer, 2000) which does not fit into one's existing belief structure.

Beliefs are common to cognitive theories (Beck, 2005; Beck, Rush, Shaw & Emery, 1979; Ellis, 1991); these theories view emotional suffering as a result of the way in which persons construct their world. The central premise behind cognitive theories is that there are complex, non-linear relationships between emotions, behaviours and a person's interpretation of an event (Beck,

2005; Beck et al., 1979; Ellis, 1991). In addition, persons create both rational and irrational beliefs that directly influence on their emotions; these beliefs tend to feed into their intermediate beliefs and core beliefs which serve to reinforce how patients view their circumstances (Beck, 2005; Beck et al., 1979). Thus, patients may view their diagnosis in terms of their self-concept, and pervading societal beliefs about cancer as well as their personal rational and irrational beliefs of cancer. If the patient's belief system is flawed, this could result in the patient's use of less effective coping strategies. In order to have appropriate coping strategies available for the fight against cancer, patients need to understand and engage in positive meaning-making processes in order to develop a set of new beliefs about themselves as competent and resilient (Beck, 2005; Beck et al., 1979).Therefore understanding how patients construct their world as a response to cancer is essential to fully understand their particular range of existential concerns and effective coping strategies.

Yalom (1980) referred to the search for meaning as a search for coherence and purpose in one's life. Having a sense of coherence suggests that persons have a sense of social consciousness, personal identity, meaning in life, a reason for existence and a stable belief of oneself, others and the world (Skaggs & Barron, 2006). Yalom (1980) further suggested that there is terrestrial, self-focused meaning and cosmic, spiritual meaning. Thus, he theorised that when these self-focused sources of meaning fall away, one needs to connect to the spiritual meaning system in order to gain purpose and define their place in the world despite their difficulties (Yalom, 1980). Yalom emphasised that meaning-making is a fundamental aspect of human existence. Thus, it can be inferred from this point that women with breast cancer attribute specific meanings to their roles and found purpose in life prior to diagnosis in contrast to the time of diagnosis which resulted in the loss of these terrestrial, self-focused meanings. In accordance with Yalom's study, women would then set out in search of spiritual meaning in order to regain their purpose in life and re-define their place in the world.

This search for meaning is described by Frankl (1970; Frankl, 1997) as a primary motivational force that is unique and specific to each individual. Frankl theorised that individuals reach out to and attain the world which is sated with others to encounter, and meaning to fulfil (Frankl, 1970; Frankl, 1978). He further added that it is an injustice to assume that individuals are

driven by meaning; that rather they are pushed by drives and pulled by meaning (Frankl, 1970; Frankl, 1978). He postulates that in order to understand individuals, they must be in the world and be at peace with themselves; therefore their meaning is unique to the individual in a particular situation. Frankl describes the existential vacuum as symptomatic of modern day society.

> *"The etiology of the existential vacuum seems to me to be a consequence of the following facts. Firstly, in contrast to an animal, no drives and instincts tell man what he must do. Second, in contrast to former times, no conventions, traditions, and values tell him what he should do; and often he does not even know what he basically wishes to do. Instead he wishes to do what other people do, or he does what other people wish him to do."* (Frankl, 1970, p 83).

In order to understand how breast cancer patients make meaning of having breast cancer; one must understand their personal existential concerns from within their context. The researcher in applying Frankl theory postulates that in the search for meaning, most breast cancer patients are required to find meaning and break away from the confined meanings that restrictive belief systems have on their lives. This need to find meaning within one's self is initiated by suffering, thus, for one to achieve transcendence, one must suffer and find meaning in this suffering in order to make sense of and fulfil their purpose in life (Frankl, 1997).The key element of this theory is that suffering unsettles the confined meanings that one subscribes too and thus leads the individual to transcend and live a more fulfilling life. Frankl further contends that faith in ultimate meaning is preceded by trust in an ultimate being. He states that one cannot break through the dimensional difference between the divine world and the human world; nevertheless one can reach out for ultimate meaning through faith which is mediated by trust (Frankl, 1970). However, as Frankl argues, meaning cannot be given or invented, it is something that must be found, it must be discovered (Frankl, 1970; Landmark, Strandmark & Wahl, 2001). In particular, breast cancer patients tend to orient themselves to their new situation by perceiving or interpreting it so that their self-concept returns; Landmark, Strandmark and Wahl (2001) stated that this led to coping within the existential vacuum, where the women in their study turned towards the future, even though results also show that they had concern for their here-and-now

situation. This turn toward the future emerged after their self-concept re-emerged focusing towards new and different values in their lives. (Landmark, Strandmark & Wahl, 2001)

Frankl further contends that although existentialism has been blamed for over-emphasising the tragic aspects of existence, this theory takes a positive position in that even death and dying are seen as potentially meaningful (Frankl, 1967). The 'tragic triad' as identified by Frankl (1967) is composed of death, pain and guilt which defines the human condition in terms of fallibility and mortality. These two constituents seem to represent the guilt and death within the 'tragic triad respectively. He contends that when individuals are threatened by the guilt of their past and their death in the future, this awareness drives them to make meaning of their life. According to this theory, breast cancer patients may reflect on their pre-cancer lives and may feel guilt for their lost or wasted opportunities of living. This may evoke a sense that one needs to improve their standard of living and thus they are pushed by the loss of temporality to seek to live more intrinsically, meaningful lives.

This need for more time is often mediated by bargaining. Bargaining is fundamental to adjustment and meaning-making however, is said by Kübler-Ross to be beneficial for brief periods. This is one of the concepts described by Kübler-Ross (1969) in her seminal work on 'Death and Dying'. Although this study on breast cancer does not explicitly focus on death or dying, this concept of the grief cycle is significant as it links with guilt as a part of psychological bargaining as a result of guilt and regret (Kübler-Ross, 1969). Various authors (Arman & Rehnsfeldt, 2003; Blinderman & Cherney, 2005; Lally, 2010; Richer & Ezer, 2000; Taylor, 2006; Westman, Bergenmar & Anderson, 2006) in the field of existential concerns have reflected on the important role of guilt in the meaning-making process. Thus the researcher understands bargaining in terms of existential concerns of women with breast cancer as a way to regain health and to retain life whereas bargaining in the terminal stages of cancer would presumably be to experience less physical pain and for some time with their family. Bargaining centres on the notion of faith and God or some higher power (Kübler-Ross, 1969). It is seen as a plea that attempts to postpone death and retain life; it often includes an offer of good behaviour, it sets self-imposed deadlines and offers implicit promises not to ask for more time. Breast cancer patients report an imperative need to look after their health and change their lifestyle

(Blinderman & Cherney, 2005; Carter et al., 2004; Lally, 2010; Landmark, Strandmark & Wahl, 2001; Logan, Hackbusch-Pinto & Grasse , 2006; Westman, Bergenmar & Anderson, 2006); this can be seen as an attempt to make reparation for living an unhealthy life which may have resulted in their diagnosis. Bargaining provides patients with time to plan to do the things that they have always wanted to do, achieve goals that they have never reached and to make up for their past mistakes (Arman & Rehnsfeldt, 2003; Kübler-Ross, 1969). This may be evident during the period in which women undergo treatment as they have the opportunity to reflect on their lives and reprioritise the opportunities they had passed up and determine how they could enrich their lives.

When values and awareness of life are altered, an expanded consciousness and openness often creates a renewed appreciation of life for women stricken with breast cancer. Therefore, breast cancer patients, when presented with this tragic triad, seem to use the loss of previously ascribed existential meaning, generated by their pain, guilt and fear of death, as a vehicle to escape their existential vacuum and engage in their new or renewed search for meaning. Hence, women take the opportunity to transform their traumatic cancer experience from being a life-threatening threat to a possible meaning-making experience. Thus, in their experience of suffering as sufferers, the struggle of women to integrate and find balance in their circumstances is strong (Arman & Rehnsfeldt, 2003); this may account for the higher levels of self-esteem and actualisation exhibited in breast cancer patients after they have made meaning (Lee et al., 2006). This hypothesis concurs with Taylor (1983) who theorised that finding positive meaning in life-threatening events, such as cancer, allows individuals to review their situation and themselves.

Underlying the aforementioned theoretical existential conceptualisations are three notions: the self and meanings held by the self; the world and the meaning society ascribes to values in life and spirituality and religion. These notions have been established earlier in this chapter by Frankl and Yalom as essential to understand how breast cancer was experienced. In addition, the common thread between the theories of existential meaning seems to be where meaning leads to transcendence and adjustment. Thus, as defined today, meaning-making is:

> *"... the ability of the person to choose the relative importance of the physical, social, emotional, religious, and intellectual stimuli that influence him or her" (*Morgan, 2003, p 114).

The process of meaning-making is dynamic as it exists in the way that we view the world (Hayslip & Hansson, 2003). When our death is impending or our continued life is compromised, our meaning of life is changed. This results in seeking adjustment to the new terms of our lives. If we view our meaning-making in terms of cognitive schema (Beck et al., 1979), when new information is received that contradicts or adds information to a current schema, the schema adjusts to encompass the new information. Similarly, our meaning-making 'schema' adjusts when new information about our mortality is presented and consequently accommodates this revised understanding and encompasses this new information. And thus meaning-making is an important tool for coping and adaptation (Hayslip & Hansson, 2003; Lee et al., 2006).

According to the Sharpe and Curran (2006), individuals must find alternative or new ways in which to assimilate their understanding of their illness into more effective adaptive views of themselves and their world. Thus, adaptation is defined as the process that maintains a positive view of the self and the world in the face of a health problem (Sharpe & Curran, 2006). It is the researcher's argument that it is through meaning-making and adaptation that effective coping and transcendence may be achieved. There are two main tasks of adaptation. Firstly, it requires facing up to the illness; the problems it creates and coping with treatment and secondly, developing a good relationship with the medical team (Guex, 1994). The first task is the most difficult task to perform as the diagnosis and consequent treatment lead to existential issues, once this is overcome then patients can focus on relationships that are important to maintaining their health. There are three sequential approaches which people use when confronted with unpleasant events. First approach is to try to change the situation; the second approach is to try to change the meaning of the situation or finally it is to try to control the stress by controlling themselves (Guex, 1994). Once the first task was completed, the second task assists patients in feeling adequately cared for and informed. Conversely, Sharpe and Curran (2006) delineate three sequential methods which they hypothesised assisted in meaning and adaptation namely:

redefining success; altering goals and meanings that had previously given life meaning and lastly, altering the meaning attached to their sense of self. Sharpe and Curran (2006) as well as Guex (1994) state that self-concepts are the least amenable to change and thus will only attempt to be modified if the earlier mechanisms prove unsuccessful. Thus ones' beliefs about the world and their place in the world are fundamental in order for meaning-making and adaptation to occur.

Meaning-making is a heatedly debated topic in psycho-oncology as researchers are unsure of its relevance for adjustment and acceptance of one's illness and if it improves patients' quality of life (Kernan & Lepore, 2009; Lee et al., 2006). Frankl (1970); Guex (1994); Hayslip and Hansson (2003); Sharpe and Curran (2006) as well as Yalom (1980) provide the view that meaning-making is central to acceptance and adjustment. Meaning-making has been suggested as a possible mechanism to explain the co-existence of positive and negative psychological states following cancer and even the ability of women to exceed and transcend their previous levels of psychological functioning (Taylor, 2000). Furthermore, Taylor (2003) as well as Tomich and Helgeson (2002), postulated that the ability to successfully reconstitute an overall meaning of life following a cancer diagnosis has been associated with general measures of psychological adjustment; in particular a greater sense of mastery, self-esteem and optimism or hope.

Despite the proliferation of studies documenting the positive relationship between meaning-making and positive well-being, Lee et al. (2006) stated that few prospective studies have been conducted to adequately test this hypothesis. A significant number of participants did not report having made meaning and these results failed to support the theory that people who search for meaning are less distressed when they find meaning than when they do not find meaning. Participants who reported a continuous search for meaning for the duration of the study were notably more distressed than those participants who reported having a relatively low frequency search for meaning over the duration of the study (Kernan & Lepore, 2009). Sharpe and Curran (2006) stated that if patients become stuck in meaning-making processes, adaptation does not occur. Theoretically, if meaning is not achieved then suffering is not transcended (Frankl, 1978) and thus adaptation does not occur. Therefore the researcher believes that it could be possible

that participants who engaged in a continuous search for meaning had become stuck and therefore had not attained meaning which resulted in further existential distress.

2.1.2 Existential Concerns

Existential concern is a term used to describe the nuances of human existence (Henouch & Danielson, 2009; Westman, Bergenmar & Anderson, 2006). Having breast cancer seems to involve uncertainties concerning the perceived loss of control which overlies the need for normality, the need for respect as a person and to be understood by another person (Halldórsdótti & Hamrin, 1996). These uncertainties can be anxiety provoking and there may be a desire to fulfil these underlying needs for security, certainty, surety and control (Halldórsdótti & Hamrin, 1996; Lally, 2010; Landmark, Strandmark & Wahl, 2001). Taylor (2006) believed that the most universal spiritual needs are those about keeping a positive perspective, finding meaning, giving love to others, and understanding or relating to God.

Psychological distress refers to a range of feelings experienced by people who may be highly stressed for situational reasons (Rustøen, Cooper & Miaskowski, 2010). The breast cancer diagnosis, treatment, and the challenges of surviving can potentially increase patients' levels of psychological distress which may influence their adaptation to and the course of their disease. If psychological distress persists and meaning-making does not occur then patients are said to experience continued suffering (Rustøen, Cooper & Miaskowski, 2010). Eriksson (1997) believed that unbearable suffering was paralysing for patients and was often unarticulated and 'suffered in silence'. However, Arman and Rehnsfeldt (2003) argue that with support from compassionate others, the individual can turn toward a development an understanding of suffering when they faced in a safe and accepting environment. For this to be achieved, their experience must be reduced to pain or anxiety in order for them to be allowed to deal with their own existential and spiritual suffering. If women had not suffered, a change process would not have been necessary, a fact that was also mentioned by Taylor (2000), who viewed suffering as the driver of transformation transcendence. The struggle to make changes in life is an indication of the women's battle with suffering and her determined fight to alleviate suffering (Arman &

Rehnsfeldt, 2003). The transformational strategy could be interpreted as measures for the alleviation of suffering and as signs of a resolute inner fight related to life and death (Arman & Rehnsfeldt, 2003).

The ultimate change that occurs is to sense of self; this is generally initiated by the physical suffering and hardships of treatment. Chemotherapy and radiation are still amongst the most feared treatments. Chemotherapy produces violent reactions which occur within the body, thus it is not the cancer but the treatment that causes a person to be ill. These treatments (chemotherapy and radiation) have multiple side-effects that range from pain, discomfort, fatigue and nausea to hair loss, rashes and burns (Henouch & Danielson, 2009) which may have severe consequences on the body and may lead to a state of psychological suffering ranging from irritation and angst to full blown depression. These side-effects of chemotherapy often result in physical change and pain and thus elicit both existential and physical suffering. This existential suffering is caused by the drastic changes to patients' bodies that impact on their self-concepts. Of these changes, hair loss is one of the most common and difficult physical changes as it affects women's self-esteem, impacts on her sexuality and femininity and could result in an existential suffering about her sense of self.

These changes were further emphasised by Westman, Bergenmar and Anderson (2006) who claimed that some participants reported changes in their sexual function such as going into early menopause, having an aversion to sexual intimacy and changes in their sexual appeal linked to the physical changes that occurred due to cancer treatment. This could be particularly distressing if women's sexual appetites had changed considerably and their view of satisfaction and sex-appeal dwindled which may have led to the questioning of their femininity (Westman, Bergenmar & Anderson, 2006). Sexuality and health are therefore important components of modern life and changes in this area seemed to precipitate and result in an existential re-evaluation (Henouch & Danielson, 2009; Saddock & Saddock, 2007; Westman, Bergenmar & Anderson, 2006). Compounding the effects on self-concept are the scars from surgery and various changes in their bodies may result in patients having significant distress which may account for one's feelings of vulnerability. In addition, radiation may lead to frustration, anger and mental and physical fatigue. Cancer appears to be a test of mental strength, however, it is the

treatment that seems to exhaust the patient of their remaining internal resources and this may further impact on their ability to cope and make-meaning of the experience.

Skrzypulec, Tobor, Drosdzol and Nowosielski (2008) and Westman, Bergenmar and Anderson (2006) stated that the breast was notably linked with sexuality, maternity, fertility and femininity and thus invasion of the breast led women to question these aspects of themselves, thus precipitating an existential crisis. Due to the arduous nature of the treatment and its emotional impact, at times it is necessary for mothers to set aside the idea of themselves as nurturer in order to tolerate the treatment. Women must then be able to tolerate the fact that they may not be able to care for their children at the standard they previously had before they commenced treatment (Henouch & Danielson, 2009; Westman, Bergenmar & Anderson, 2006). This may lead to feelings of inadequacy, disappointment in one's self and doubting one's capacity to be a good mother. Maternity is additionally questioned in women who had not yet had children as chemotherapy and radiation can severely hinder fertility. The loss of fertility was of significance to cancer patients as these women may also have had to grieve the loss of not being able to carry a child and may have engaged in issues around attachment with their children. These issues have been indirectly linked with existential concerns as they affect the woman's sense of self, views of hope, social relationships, the need to love and be loved and connectedness with others (Henouch & Danielson, 2009; Westman, Bergenmar & Anderson, 2006).

The needs for normality, to fit in and be part of a community are essential to our sense of self and our group affiliation (Carter et al., 2004; Logan, Hackbusch-Pinto & Grasse, 2006; Westman, Bergenmar & Anderson, 2006). When a person experiences physical change that does not fall within the normal range of experience such as cancer treatment, this can result in one feeling different and deficient their previous ties and affiliations. Westman, Bergenmar and Anderson (2006) stated that participants reflected on their strong need to maintain a sense of normality in their life. This was obtained by staying in shape, being healthy and 'looking normal'. In many studies (Carter et al., 2004; Logan, Hackbusch-Pinto & Grasse , 2006; Westman, Bergenmar & Anderson, 2006) women made reference to life before their diagnosis or life without their diagnosis; this was mainly used to describe the effects of any life restrictions resulting from their illness. Carter et al. (2004) stated that despite acknowledging attempts to

maintain normal activities in the early stages of their illness, participants identified significant and persistent restrictions in their role functions. This was primarily expressed as adapting to what was no longer 'normal' rather than making adjustments for their impending death. It seemed that breast cancer patients engaged in a re-appraisal of their identities and roles in order to incorporate these changes into their sense of self.

An additional key concept in the literature is '*taking charge'*. This concept was concerned with patient's ability to identify and actualise their needs, with the position of control depending on their ideal ways of achieving these outcomes (Carter et al., 2004). The findings suggest that taking charge represents the central theme within the participants' range of experience and this mediates all other themes. An essential outcome from the patient's perspective is the preservation of dignity; by addressing issues around dignity, health professionals may assist patients in taking charge (Carter et al., 2004) and thus maintaining their internal locus of control. Landmark, Strandmark and Wahl (2004) concluded from their study that women turned towards the future when women created self-understanding in their unpredictable lives by focusing towards new and different values in their lives (Landmark, Strandmark & Wahl, 2004). This turn towards the future insinuates that participants engage in strategies of hope and positivism (Chi, 2007). When a person is faced with their own mortality, such as receiving a diagnosis of cancer, an existential re-evaluation process seems to result. This re-evaluation affects the person's internal locus of control (i.e. their position of control in their own lives) (Carter et al., 2004). The struggle that one goes through when faced by such an existential re-evaluation is enormous especially since persons react by using different mechanisms to maintain one's internal locus of control in order to take charge of their life. This concept is further reinforced by the work by Logan, Hackbusch-Pinto and Grasse (2006) who stated that patients would at times voluntarily isolate themselves from others in order to foster and preserve and guard their inner strength. This is indicative of taking charge of their environment in order to preserve their resources and make meaning. During this period, patients seemed to employ two strategies of control namely: 'spiritual coping' and 'social coping'. 'Spiritual coping' occurred when patients isolated themselves in order to reflect on their experience and their faith, whereas 'social coping' was the utilised to elicit emotional support from one's family and friends.

Social support is a beneficial resource for women with breast cancer (Halldórsdótti & Hamrin, 1996; Sammarco, 2001; Westman, Bergenmar & Anderson, 2006); however some women perceived it as disempowering. Sammarco (2001) stated that families often exhibited an increased need for social support due to the well-being in the marital relationship and adjustment of children frequently being threatened by the occurrence of breast cancer in younger women. Sammarco further contends that some women with breast cancer frequently perceive offered support as inadequate or unhelpful and may perceive the supportive behaviours that come from one person as inappropriate or stressful when provided by another. Logan, Hackbusch-Pinto and Grasse (2006) results differed from Sammarco's study (2001) as social strategies were frequently used when a woman's inner strength was weakening. In this study, close relationships with friends and family were valued as they served as a distraction to take one's mind off the possibility of cancer and death and assisted in preventing overwhelming sadness or depression. Halldórsdótti and Hamrin (1996) provided support for this as they found that the social context and social support from partner, family, friends, relatives and especially health care professionals were important for improved adaptation and survival of cancer patients. Furthermore, the altruistic need to share one's knowledge, thoughts and feelings with other breast cancer patients was seen as meaningful and helping and a manner in which to create meaning (Landmark, Strandmark & Wahl, 2004; Logan, Hackbusch-Pinto & Grasse, 2006).

Faith, religion and belief are crucial to a person's concept of self and how they relate to the world. Most cultures view the spirit as a seat of reason that fosters hope, truth and morality (Moore & Williamson, 2003). In times of crisis, one generally turns to one's faith. Chi (2007) found that religion was a strong predictor of effective coping and positive adjustment to illness as it facilitated hope amongst patients. Furthermore, Logan, Hackbusch-Pinto and Grasse (2006) emphasised that breast cancer patients employed spiritual coping strategies to focus on intrinsic needs and utilise their internal resources of faith, hope, positivity and meaning. Taylor (2006) provided support for this when she found that religious people were more likely to consider spiritual needs important as religion offered them awareness, emotional comfort and language for experiencing these spiritual needs. Morgan (2003) defined spirituality as the perception of the world, the person's philosophy of the world and the sense of meaning that one holds about world and themselves. Similarly Taylor (2006) reported that the most universal spiritual needs are those

about keeping a positive perspective, finding meaning, showing compassion and understanding or relating to God. Thus, the fundamental elements of spirituality are closely linked to loving God and having relationships with others.

Spiritual well-being is characterised most frequently in terms of existential and religious domains. Ferrell, Grant, Funk, Otis-Green and Garcia (1998) characterised spiritual well-being as encompassing feelings of uncertainty, hopefulness, purpose for living, positive spiritual changes, increased life meaning and the importance of spiritual activities. This domain has been defined as the ability to maintain hope and derive meaning from the cancer experience that is characterized by uncertainty. Spiritual well-being involves issues of transcendence and is enhanced by one's religion and other sources of spiritual support such as interconnectedness (Ferrell et al., 1998). The notion of the need for spirituality is further reinforced by a study by Logan, Hackbusch-Pinto and Grasse (2006) where the perceptions of spirituality in 20 women who had undergone a breast diagnostic were explored. The study illustrated that most women used prayer and their relationship with God as strategies to meet their spiritual needs. These women reported that rather than going to church or to church activities, they utilised their thoughts and prayers to God. Some women in the study however did not feel that spirituality was linked with being religious and went on to state that they would not see a chaplain as they did not want someone else’s views forced on them. This may be further evidence of women controlling their environment in order to reduce their distress as they possibly did not have the internal resources to engage with the role that spirituality and religion have within their diagnosis.

Hope is a belief that a situation can be modified and that there is a way out of difficult situations; .i.e. the belief that there are better days to come (Rustøen, Cooper & Miaskowski, 2010). Chi (2007) found that the level of hope was significantly related to the level of coping and that patients who exhibited high levels of hope coped with their disease more effectively through the use of active acceptance, normal living and reconciling with life and death. O’Connor, Wicker and Germino (1990) provided support for this as they found that hope is an important resource that influences an individual’s ability to cope with stressful, life-threatening situations. However, it is not completely clear whether hope is a result of successful coping or is a coping strategy *per se*. Rustøen, Cooper and Miaskowski (2010) found that hope mediates the relationship between

a person’s health status and their psychological distress. This finding suggests that hope is an important resource for cancer patients as it can affect how one views oneself, ones’ health status and ones’ future possibilities. This was evident in that cancer patients with a poorer health status, lower levels of hope and higher levels of psychological distress were predicted to have lower levels of life satisfaction (Rustøen, Cooper & Miaskowski, 2010). Therefore, an equally important finding from this study is that hope provides a particularly powerful mediating relationship between psychological distress and life satisfaction.

With regard to hope, there are two conflicts to be resolved. The first conflict occurs when there is a lack of hope from family or staff. If this hope is discouraged, patients seem to experience despair and despondency. The second conflict occurs when the family lacks the ability to deal with person’s acceptance of death and try to cling to hope. This conflict will also result in despair when the patient has come to terms with their mortality but the family refuses to accept the person’s point of view. Consequently, this pressure from family to keep fighting for hope takes away from the patient’s wish to die with dignity (Kübler-Ross, 1969). There is a balance that must be struck in the above situations in order to provide the patients with a comfortable space in which to come to terms with their diagnosis and make meaning within their family context. Kübler-Ross (1969) wisely reflected that one should never fully deprive any patient of hope; even terminal patients have to have some sense of hope. All patients contain some degree of hope and use this to cope especially in difficult times. If a patient stops hoping, it is a sign of imminent death (Kübler-Ross, 1969). This facilitation of hope by practitioners fosters good social support thus increasing the patients’ quality of life (Logan, Hackbusch-Pinto & Grasse, 2006).

2.2 Contextual and Cultural Perspective

The importance of culture in shaping beliefs and meanings has long been recognised. There is no one universally accepted definition for culture but the role of culture is reflected in specific behaviours and activities of individuals such as dietary practices, religious observances and

bereavement rituals and in how people define their place in the world. It has been communicated through many multigenerational modes of transmission such as myths and legends, television, books and the mass media; these modes of communication transmit the current perceptions of society regarding beliefs pertaining to health, illness and death as well as in this instance cancer (Hayslip & Hansson, 2003). Culture has also been found to have an impact on certain beliefs pertaining to health and illness. Donnelly (1995) suggested that it is important for nurses to understand patients' cultures in terms of models of reality. She considered cultural models as "the pool of meanings fashioned within and available to a community to make collective sense of a shared experience" (Donnelly, 1995, p 7).

In 2002, there were approximately 64 000 new cancer cases diagnosed in Southern Africa compared with an average of 49 939 cases per year reported between 1993 and 1995 (CancerStats, 2005; Sitas, Madhoo & Wessie, 1998). Fregene and Newman (2005) stated that mortality rates were disproportionally higher amongst Black women despite the fact that Black women had a relatively lower incidence rate. This increase in new cancer cases may be attributed to the westernisation of African countries, in addition to the lack of education, lack of early detection and the seeking alternative treatments before presenting at hospitals (CancerStats 2005; Fregene & Newman, 2005; Lo Castro & Schlebusch, 2006).

Furthermore, there is a lack of information regarding the psychological experience of breast cancer within the South African context, particularly within the Black population where existing psychological studies have focused mainly on the healthy breast or instances of non-malignant disease whereas the White population was studied predominantly from a western perspective (Schlebusch & van Oers, 1999). Fregene and Newman (2005) concluded that this lack of information in African countries is due to the lack of financial resources in sub-Saharan Africa; this was apparent in fewer treatment facilities and hospitals with limited staff and diagnostic equipment. Thus the treatment of breast cancer in sub-Saharan Africa was largely limited to surgery because of advanced stage at presentation and limited access to diagnostic imaging tools. Pillay (2001) as well as Krombein and de Villiers (2006) offered support for this when they stated that South African hospitals are over-burdened and treatment facilities were not geared

towards catering for the psychological needs of cancer patients, especially in terms of screening and educational interventions.

According to Krombein and de Villiers (2006), South African women believe that their health is self-determined, thus, when illnesses, such as cancer encroach on their lives, women experience feelings of guilt. This is significant as it was evident that these women avoid screening out of fear of discovery of cancer as it seemed unbearable for women to believe that they had brought illness onto themselves and as such avoidance was used as a defence mechanism in order to protect their psyche. Women felt that if they were aware of their diagnosis then that would translate into death. This fear was rooted in anxiety rather than in cancer and fear seemed to cause immense suffering. In addition, the lack of knowledge of cancer had been noted as significant in women's perceptions of cancer and screening and seemed to account for insufficient screening practices (Jepson, Kessler, Portnoy & Gibbs, 1991; Krombein & de Villiers, 2006). Jepson, Kessler, Portnoy and Gibbs (1991) stated that when controlled for knowledge variables, all other opinions and perceptions of cancer were non-significant and thus it was established here that it is important for South African women to have accurate information regarding the possible etiology and treatment of breast cancer. However cultural beliefs are said to affect the health beliefs women hold (Schlebusch & van Oers, 1999) and thus researchers need to be sensitive to cultural diversity amongst the breast cancer populations (Pillay, 2002; Krombein & de Villiers, 2006; Vorobiof, Sitas & Vorobiof, 2001).

Culture is delineated into two orientations, individualistic orientations and collectivistic orientations. Members of predominantly individualistic cultures view 'the self' as independent of groups, whereas in collectivistic cultures 'the self' is seen as part of the group (Schouten & Meeuwesen, 2006). Individualistic orientations value characteristics such as achievement, autonomy, independence and self-reliance whereas collectivistic orientations seem to place greater emphasis on sense of community, dependence, co-operation, friendliness and interpersonal relationships (Schouten & Meeuwesen, 2006; Sparks & Villagran, 2009). It must be noted that no country is absolute in their cultural orientation, there is no country that is completely individualistic or collectivistic rather, they are a combination of the two which takes individual and group differences into account (Sparks & Villagran, 2009). As stated earlier,

cultural backgrounds have a significant influence on health beliefs and must be taken into account when determining health-risk behaviour (Schlebusch & van Oers, 1999). Therefore, individualism and collectivism must be examined in order to account for how cancer patients experience different cultural interpretations and perspectives of their diagnosis.

It is evident that cancer patients from individualistic cultures tend to focus more on the impact of cancer on their self-identity and career success whereas collectivistic cancer patients tend to focus on communication and the impact of cancer on group harmony and functioning (Sparks & Villagran, 2009). In individualistic cultures, cancer patients may view their cancer as a more personal matter or may resist relying on others during this time and they typically desire to maintain control of their bodies and their own lives (Logan, Hackbusch-Pinto & Grasse, 2006; Sparks & Villagran, 2009). In collectivistic cultures, the cancer diagnosis is not seen as an isolating event, but rather it is often seen as a reason for increasing family cohesion during times of treatment (Sparks & Villagran, 2009). In contrast, family members from collectivistic cultures are more likely to play a major role during the treatment phase of cancer and this may result in several family members attending doctors' visits in order to provide social support to the patient (Vorobiof, Sitas & Vorobiof, 2001). In countries with collectivistic orientations, there is more likely to be social stigma attached to a cancer diagnosis (Krombein & de Villiers, 2006; Sparks & Villagran, 2009). Black South African women stated that there is stigma attached to cancer and this seemed to be rooted in cultural taboos passed down from generation to generation (Krombein & de Villiers, 2006). They further added that cancer was not discussed openly when they were children and this fostered this taboo in their lives (Krombein & de Villiers, 2006). Sparks and Villagran (2009) extended this and explained that stigma occurred because of cultural misperceptions about what it means to have cancer.

South Africa consists of many diverse cultures; some indigenous African cultures hold the belief that the etiology of cancer is a reflection of conflicts that individuals face especially in terms of their social relationships. This conflict seemed to manifest as discord between the individual and their ancestors which resulted in them being punished by their ancestors (Pillay, 2002; Schlebusch & van Oers, 1999). In some collectivistic cultures in South Africa, a cancer diagnosis may have been seen as a sign that the individual had lived an unbalanced life or had indulged in

an unhealthy lifestyle (Krombein & de Villiers, 2006; Pillay, 2002; Schlebusch & van Oers, 1999; Vorobiof, Sitas & Vorobiof, 2001). This seemed to evoke feelings of guilt and therefore it is postulated that individuals from collectivistic cultures try to minimise the seriousness of their symptoms or even fail to acknowledge their symptoms in order shield their families and themselves from the guilt and stigma attached to cancer (Sparks & Villagran, 2009). Thus, patients allow their cancer to progress until they can no longer manage the pain which allows the cancer to develop and spread or become untreatable. Sparks and Villagran (2009) further added that cancer patients who experienced discrimination due to cultural misperceptions about cancer suffer two injustices namely, cancer itself and unfair discrimination due to having cancer.

No country is monotheistic and thus South African cultures are diverse and ubiquitous, where levels of integration and acculturation have led individuals to integrate varying degrees of different cultural concepts into their sense of self. Studies conducted on urban and the rural Black women found that younger urban Black women identified less with their cultural practices and adopted more western outlooks (Pillay, 2002; Vorobiof, Sitas & Vorobiof, 2001). These studies observed that younger Black women had higher levels of acculturation which influenced the way in which they think and resulted in them being more susceptible to the more accurate exposure that they received from formal education, media and the Western world regarding breast cancer (Pillay, 2002; Vorobiof, Sitas & Vorobiof, 2001). This resulted in more urban Black women having experienced modern medical standards and engaging in the freedom to choose to obtain medical treatment from the source of their choice (Pillay, 1996; Vorobiof, Sitas & Vorobiof, 2001). Western societies, the western world and western outlooks are terms that have been used frequently in literature, in this study the West will be operationalised as standards coming from the Americas and Europe. The author now turns her attention to a discussion of empirical data from the South African context.

Traditional and non-traditional medicine was viewed differently within rural and urban contexts. In rural contexts, indigenous healers were seen as the only legitimate and successful healers of cancer and modern medical approaches were viewed with suspicion (Vorobiof, Sitas & Vorobiof, 2001). This is significant as 80% of Black women are said to access traditional healing (A. Pillay, 1996; B. Pillay, 2002; Vorobiof, Sitas & Vorobiof, 2001). Furthermore, some patients

with breast cancer stated that they were not necessarily the key decision-makers with regard to the different therapeutic choices available; due to their collectivistic culture, this seemed to be a collaborative process involving traditional healers, family members and sometimes elders of the community. In addition to making decisions, this support network was used as a coping mechanism whereby members provided mutual economic and emotional support, with the members relying on the social ties created and maintained in such groups (Vorobiof, Sitas & Vorobiof, 2001). Therefore, this study provided valuable information into the rural and urban perceptions of Black, South African breast cancer patients towards coping and group affiliations.

Pillay (1996), Schlebusch and van Oers (1999) as well as Vorobiof, Sitas and Vorobiof (2001) found that Black and White women with breast cancer experienced their disease differently. In particular, there was a marked difference in the level of psychological distress associated with their disease where Black patients were found to experience higher levels of body image dysphoria and depression than White participants whereas White participants seemed to utilise different, possibly more effective adaptive adjustment styles than Black participants (Schlebusch & van Oers, 1999). In addition, White participants reported less distress arising from somatisation; since a greater proportion of the Black patient sample presented for treatment with their disease at a more advanced stage of progression, this may in part account for the elevated level of somatic responses displayed; however this may be further explained by cultural differences as mentioned by Vorobiof, Sitas and Vorobiof (2001).

Therefore, it was postulated that Black patients could be regarded as being at greater risk than White participants for requiring psychological intervention due to their covert existential suffering. Schlebusch and van Oers (1999) offered a partial explanation for this by stating that the difference could be accounted for in terms of culturally diverse views of health and disease, and as well as the historical lack of psycho-oncological services offered to Black patients. Vorobiof, Sitas and Vorobiof (2001) expanded on this when they conducted a study on multi-racial incidence and etiological causes of breast cancer. They found that Black patients located etiology of their cancer within an indigenous African belief framework. Members of the traditional African community often subscribed to the belief that witchcraft had caused their cancer and therefore, their first priority was to reverse the sorcery. As a result, patients sought

assistance from traditional healers as a way of dealing with the cause of the disease. Modern medicine was scoffed upon and the concept of 'a painless breast lump' being cancerous and potentially terminal was difficult for many Black, rural women to grasp.

In addition, research has suggested that certain symptoms are culturally more acceptable and bring greater sympathetic responses and therefore may be reported more frequently. Mechanic (1968) stated that patients who utilise non-verbal communication to express psychological distress tend to come from cultural groups in which the expression of emotional distress is inhibited. This led Schlebusch and van Oers (1999) to postulate that some patients within the Black participant group may have experienced somatised psychological distress, as complaining was discouraged within their cultural perspective. Black participants within their cultural context conceptualise disease as affecting both spiritual and physical elements; therefore the lower anxiety and depression levels experienced may be better accounted for by the extent to which this more holistic view of disease enabled them to be less anxious about its outcome. Conversely, it is possible that some participants may have perceived themselves as being punished for wrongdoing and bearing the brunt of ancestral anger and experienced feelings of guilt. Schlebusch and van Oers (1999) stated that this correlated with previous results as guilt often exists as part of a depressive state.

Predominant adjustment styles utilised by the Black participant group namely: hopelessness, helplessness and denial, was possibly indicative of a perception of not being in control (Schlebusch & van Oers, 1999). This may account for their greater degree of depression as loss of control may be a factor that influences the experience of depression. Participants within the Black participant group exhibited a higher degree of body image dysphoria particularly in relation to feelings about physical appearance in situations of social scrutiny. As Black participants subscribe to a collectivistic culture, this seemed like an accurate conclusion. The effect of breast cancer is pervasive in all avenues of life from the way the patient views herself, to the way her community members view her. The loss of control, normality, sense of self and experiencing of suffering seems to have permanently changed participants outlook and meaning in life.

2.3 Conclusion

Divergent opinions exist amongst Guex (1994); Hayslip and Hansson (2003); Kernan and Lepore (2009); Lee et al. (2006); Sharpe and Curran (2006); Taylor (2000) and Tomich and Helgeson (2002) regarding whether meaning-making is necessary for adaptation to breast cancer. Although the answer is not clear, there is evidence that receiving a cancer diagnosis seems to force women into facing their mortality which elicits various existential concerns. These concerns seemed to be deeply rooted in cultural and contextual perspectives and thus one cannot remove the individual and their existential concerns from the context in which they generate meaning. Fundamental existential concerns reflected loss of control, normality, sense of self and the experience of suffering which seemed to permanently change participants' outlook and meaning in life. Frankl (1970) states that in order to break free from the constructions and meanings that society imposes on us; one must experience true suffering and have the will to find meaning and overcome it. It is through this process that meaning and adaptation occur and women with breast cancer can find purpose and meaning again. Thus, the theories which underlie existentialism and meaning-making as well as the cultural factors which co-construct these women's existential concerns are an important background to inform an understanding of the data presented in Chapter Four.

Chapter 3: Methods

Qualitative psychology has gained prominence in recent years and aims to provide rich narratives of phenomena under investigation. It is generally linked with describing, exploring and interpreting the experience of participants (Smith, 2006). Therefore, the lived experiences of participants with breast cancer may be unique, in addition they may also qualify that all experiences have universal features such as discursiveness, inter-subjectivity, selfhood, subjective embodiment and temporality (Ashworth, 2006). Husserl (1970 as cited in Ashworth, 2006) stated that human experience is not a matter of regimented response to the 'variable' that is assumed to be in operation but rather the experience of a system of interrelated meanings that are bound up in a totality; that is what researchers can attend to in the context of understanding the lived-experience in all its complexity and fluidity (Coyle, 2007). It is for this reason that contextual methods in the form of qualitative methods have been employed in this study.

3.1 Research Questions

- What did patients consider as existential issues in relation to their experience of cancer?
- How did breast cancer patients make meaning of their diagnosis and ensuing life circumstances in order to cope?

3.2 Procedures

In order to obtain ethical clearance to conduct the study, the Ethics Committee of the University of the Witwatersrand was consulted and presented with a research proposal. Ethical clearance was obtained in May 2010 (Appendix A). After this, the researcher obtained consent from The Cancer Association of South Africa and The Breast Health Foundation to recruit participants from these organisations. Both organisations assisted in circulating the study's Participant Information Sheet (Appendix B) to the members on their data bases. The Breast Health Foundation gave the researcher permission to do a short presentation on the study at their 5th

anniversary party. The researcher invited the attendees of this function to participate in the study and to assist in recruiting other participants for this study.

Interviews with eight participants were held between July and September 2010. The participants were contacted telephonically to confirm their participation in the study and an interview was subsequently scheduled. The interviews were held at locations that were convenient for the participants and lasted approximately 30-70 minutes in length. Most interviews ranged from 40-50 minutes whereas one interview was 30 minutes and another was 70 minutes. The researcher used the demographic questions in the interview schedule (Appendix F) and the research consent process (Appendices C-E) to establish rapport. Participants were informed of their rights and written consent was obtained before the data was collected. Due to the flexible nature of semi-structured interview, the participant was allowed to guide the interview while the researcher used various probing questions to elicit deeper responses. The researcher recorded the interviews on audiotape in order to ensure accuracy.

3.3 Participants

The participants were selected into the study according to selection criteria. These criteria consisted of the following: participants had to be diagnosed with breast cancer, had terminated oncological treatment in the last year, and had not undergone mastectomy surgery. Furthermore, these participants had to be fluent in English. Nine women volunteered for the study, however one prospective participant who met the inclusion criteria but struggled with English fluency; this interview was excluded.

The study consisted of eight South African women who had ended treatment within 4-12 months at the time of the interview. Furthermore, all participants were currently on hormone treatment. There were four Black and four White participants in the study who were purposefully selected into the study. They were aged between 30 and 57 years and were from diverse cultural and religious backgrounds. Four of the participants stated that they were Christian (two White participants and two Black participants) while the other participants reflected on their cultural affiliations in terms of language. The remaining White participants reflected that were from Afrikaans and Italian backgrounds respectively, while the remaining Black participants stated

that they were Zulu and Xhosa respectively. Most (88%) of the participants stated that they had at least one child, varying in age from 6 to 23 years, and were in long-term relationships; either in the form of marriage or committed relationships. One participant did not have children nor was she in a committed relationship.

The researcher noticed that the shortest interview was conducted with Participant 8 who seemed to reach saturation of experience quite early. She expressed a particularly positive view and did not reflect to a great extent the existential distress that she may have felt, even when probed for. She did engage in positive restructuring and reflected important cultural views. Therefore the interview was included. The longer of the two interviews was conducted with Participant 2 who seemed to have difficulty accessing all domains of her experience in their entirety. She was exceptionally emotional and she used the interview as an opportunity to holistically integrate her experience.

3.4 Research Instruments

Interviews are used in qualitative research to gain a subjective account of the experiences of the participants (Ritchie, 2003). One semi-structured interview was held with each participant and was used to guide the flow of the interview. The researcher adapted her style of questioning to better suit the participant's style of answering as well as guided the flow of the interview. This was important for maintaining rapport and creating a safe and contained environment in order to elicit detailed explanations of participant's existential domains as well as ensuring that the focus of the interview was maintained. The interview schedule (Appendix F) consisted of two components: demographic questions regarding participants' age, religious and cultural affiliations, treatment status as well as the marital and employment status, and the research question and probing questions.

An interview schedule was developed, based on the literature by Allen, Savadatti and Levy, (2009); Arman and Rehnsfeldt, (2003); Henouch and Danielson, (2009) and Landmark, Strandmark and Wahl, (2001) concerning the existential domains of experience of having breast cancer. It focussed on two main themes: existential concerns and meaning-making. The interview contained five questions and additional non-directive probing questions that where

necessary to elicit more depth responses. For example the three of the main questions were: "Could you please, in as much detail as possible, tell me what it was like for you, having breast cancer?"; "In what ways has breast cancer has affected your life?" and "From this experience what would you say gave you meaning?" Probes and reflections were often used to acquire elaborations on an idea for example: "It sounds like social support was important for you."

3. 5 Data Analysis

Thematic content analysis is the process of analysis used here to uncover and analyse recurrent themes or patterns that were elicited from participants (Ritchie, 2003). Thematic analysis is not linked to any particular pre-existing theoretical framework and therefore it can be used within different theoretical frameworks; its theoretical freedom provides an accommodating and useful research tool which can potentially provide a rich and comprehensive, yet intricate account of the data (Braun & Clarke, 2006). Thematic content analysis was utilised within the contextualist method. This method acknowledges the ways in which individuals make meaning of their experiences as well as the ways that the broader social context enriches the meanings that people subscribe to their realities while preserving focus on the material and other limits of 'reality' (Braun & Clarke, 2006).

The researcher listened to the audio-recording of each participant to better gauge the richness of the data as well as to determine if saturation had been met. These audio-recordings were transcribed verbatim. The transcribed interviews were then analysed using Patton's (1987) steps of Thematic Content Analysis (TCA) which revealed different key themes from the text that were allowed to develop inductively. The context in which the data was collected as well as the content in the form of themes were both analysed during this type of analysis (Spencer, Ritchie & O'Connor, 2003); this allowed for a more detailed and nuanced account of particular themes or group of themes within the data. The researcher read through the transcripts several times in order to gain a holistic view of the data and to develop key concepts and themes that she thought represented the underlying concepts of the study. She focused on how the themes were introduced by the participant and the frequency that each participant brought up each specific theme as well as the latent content of the interview.

The researcher identified and coded similar, significant concepts in the transcripts. These were then roughly clustered together, once clustered; the identified concepts were grouped into categories that represented the responses of the participants. For example, a participant said:

> *"I realised that having money and having material things, it's really not the real life. Real life is about spending time with people you love and doing good to other people, like now, what I'm doing when I'm educating the community about breast cancer"*

This quotation was categorised under: '**meaning-making for self'** and **'meaning-making for others'**. These steps were repeated to ensure that all relevant categories were noted and that no relevant data was overlooked. These categories were condensed into similar clusters; in turn these clusters were evaluated and grouped into subthemes. For example: '**meaning-making for self'** and '**meaning-making for others'** were clustered into the subtheme: '**meaning-making'**. These sub-themes and topics were condensed and summarised into the classification of themes. And '**meaning-making'**, '**coping'** and '**religion and spirituality'** were pulled together to form the theme: '**Existential Meaning'**. Finally, the researcher used the above summaries to assess relationships between the themes.

3.6 Self-Reflexivity

In exploring the experience and meaning of participants, researchers seem to engage in interpretative activities in order to try and make sense of the participants' worlds; thus no qualitative study can be analysed without the lens of the researcher (Lyons, 2007). Furthermore, the researcher's pre-existing conceptions of breast cancer and existential experience may be actively linked to how she tried to describe and account for the participants experiences (Lyon, 2007). This was evident as the researcher found herself fascinated by the 'inner strength' that participants seemed to display. She wished to understand and explore this more which was done through the participants' narratives. This interest seemed to guide the researcher's interviewing technique which may have detracted away from some of the more existential experiences of breast cancer. The researcher was confronted with her own views of life and death, religion, spirituality and the concept of being a woman. Thus, it seems that only once one is immersed in dialogue with the data, can one be aware of their personal theories and engage in a process of critical reflection and act as a medium of analysis and critique (Freshwater & Avis, 2004).

In her journey to ensure that the participants were treated as sensitively as possible, the researcher turned to the writings of Finch (1984) and Oakley (1999) who provided insight into the ethics of interviewing women. Finch (1984) stated that the ease at which a woman researcher can get women to talk about their experiences is not dependant on their level of skill, but upon the researcher's identity as a woman. The researcher was initially sceptical but experienced this as she was generously invited into participants' homes and introduced to their family members; there seemed to be an eagerness to share their story, even though some participants seemed initially anxious. She found that the participants expressed their surprise as to how readily they were able to talk about their experience of hsaving breast cancer. This identification of women participants with their women researchers must be acknowledged as there is an exploitative potential which may makes women particularly vulnerable as research participants (Finch, 1984; Oakley, 1999).

The researcher concedes that the knowledge and experience of this during the research process may have made her cautious in her line of questioning as she was trying to be as unobtrusive as possible while trying to ensure that she did not purposeful exploit the participants. The researcher in hindsight believed that there were some avenues in which she could have probed further in which to elicit more meaningful responses; this was particularly evident with Participant 8 who reached saturation fairly quickly. The researcher felt that possibly the client had not experienced her cancer as being as transcending as she had described and that this was possibly a coping mechanism which she had developed. The researcher did not question Participant 8 to her full extent as there was a fear that she may decompensate her. In retrospect, the researcher felt that if she had more experience in containment, that this would have elicited more meaningful, depth responses. Furthermore, if done in a containing manner, this may have allowed Participant 8 to holistically represent and integrate her unique experience of having breast cancer.

3.7 Ethical considerations

As this study called for an engagement of participants with specific regard to their existential issues after their breast cancer diagnosis; there may have been risks to some participants who had not achieved a satisfactory level of adjustment. According to the DSM IV-TR (American

Psychiatric Association, 2001; Saddock & Saddock, 2007) adjustment generally occurs between 3-6 months after a stressor; thus the period during which the participants were interviewed was a period greatly associated with adjustment to the diagnosis and treatment regimen (Sharpe & Curran, 2006; Lally, 2010).

All information was provided to participants in the form of personal communication, the Participant Information Sheet (Appendix B) and Consent forms (Appendix E-E). The aim of the study was clearly stated and explained therefore no deception was used during this study. Thereafter the three consent forms were issued to the participants in order to obtain consent for them to be interviewed and recorded as well as for the use quotations directly from the interview session. Participants were made aware of the voluntary nature of the study; as well as their rights to withdraw and their right to refuse to answer questions which made them uncomfortable. Due to the face-to-face nature of the interview, anonymity could not be guaranteed however, confidentially was maintained in a limited manner, only the researcher and her supervisor had access to the data. Privacy was ensured as no identifying information would be revealed. Participants were informed that even though quotes and themes would be discussed in the research report, that they would be identified by a numerical code at all times, for example Participant 1. The participants indicated that they fully understood the terms and conditions of the research and completed all three of these forms before any data from the prospective participant was collected and analysed.

Each participant was informed of the generalised counselling services that were available to them in the form of Bosom Buddies and Reach for Recovery-cancer support groups; the contact details were included on the participant information sheet. After the interviews were concluded, the interviewer asked them if they had experienced any significant distress or negative effects due to participating in the research and if so she would help them by offering specialised counselling at no cost to them. These participants would have been supplied the telephone numbers to the South African Depression and Anxiety Group (SADAG).This offer was not taken up by any participants in the study. The research material was stored in a password protected computer file for the duration of the study. On completion of the study, the audio-recordings were deleted from the researcher's computer and hard copy transcripts were stored safely for use in further research. Participants were informed that they could access the findings of the study on a website in January 2011.

Chapter 4: Results

The research questions aimed to determine the existential concerns of South African women with breast cancer as well as an exploration of how these women made meaning of their diagnosis and ensuing life circumstances. Thematic content analysis of women's narratives reduced the data to three themes. Furthermore seven existential components were uncovered namely: meaning; sense of control; self-esteem; being positive; being with family and relating to God and others. Each existential component represented the range of women's thoughts and behaviours which were condensed into three themes: existential reflections, existential meaning and role of culture. These themes were not linear nor were these discrete entities; rather they exist as interconnected processes that are influenced and affected each other.

4.1 Existential Reflections of Breast Cancer

The study aimed to gain a perspective of the experience of existential changes of South African women with breast cancer. Thus an important theme that arose related to the changes that women went through on receiving a cancer diagnosis. Each participant's experiences of having breast cancer, from the time of diagnosis until termination of treatment and on into remission, was unique and profoundly subjective. In addition, two subthemes (existential suffering and values in life) were identified and were explored in order to highlight these subtle nuances of the experience of cancer participants.

4.1.1 Existential Suffering

Suffering is characterised by a sudden disruption of life, loss of temporality and an awareness of death that elicited distress. For these participants with cancer, physical and emotional suffering was experienced in various degrees; this was most evident when women received their diagnosis as well as while they underwent treatment and subsequently ended treatment.

Existential suffering is a reflection of the emotional suffering that one experiences from loss, despair, fear, uncertainty and guilt. Most women reacted to the news of receiving a diagnosis of cancer with uncertainty for the future. This uncertainty was additionally seen at all stages of cancer, from diagnosis to treatment termination and remission. The uncertainty of one's temporality seems to evoke feelings of denial, disbelief, anger and emotional numbness to mild shock as was also the case with these participants. These women felt uncertainty over the prospect of death as well as whether the treatment would be successful. In addition, once treatment had ceased, there was uncertainty around recurrence which caused feared and distress in most of the women. More daunting was the fear that the cancer would recur in another organ. Breast cancer was viewed as a cancer that was relatively easier to treat with a better prognosis, however, cancer in other areas of the body were highly feared because this indicated that the cancer had metastasised into the body as a life-threatening form of cancer. This renewed threat on their life was viewed in a negative light, even in participants who had quickly established meaning. When questioned about hopes for the future, few participants chose to engage with issues not related to recurrence; this reflected appropriate levels of insight. Participants seemed to focus on the present and the uncertainty of the future as well as attempted to minimise negative thinking in order to decrease suffering. However, participants stated that reminders of cancer were frequent even though they did not want recurrence to be a chief focus in their lives. It seemed to always be at the back of their minds and in some women this had led to hyper-vigilance when changes occurred in their body or when unexplained aches and pains were felt.

> *Participant 7: "Well, my worst fear is that I may have a recurrence of cancer, you know, as much as I am a stronger person with where I am now I don't think I would be able to accept it so my worst fear is the recurrence of cancer... To show that sometimes it does affect me, sometimes I would have this pain and I would go to the doctor and the doctor would say no that there is nothing to worry about so it made me worry a lot about my health."*

In addition, some seemed particularly vulnerable to the loss of monitoring by medical staff. Some women expressed some apprehension due to their decreased monitoring which led to

anxiety about being independent from the medical team. Participant 1 seemed particularly concerned by the loss of monitoring and recounted the following.

> "*That is actually very worrying for me, I'll tell you why, because while I was busy with treatment, the doctors were always there all the time... So all the time they are around you all the time, they monitor your progress all the time and now all of a sudden, even though I still go see him, there's these gaps and I feel like saying what if something happens.*".

From the narratives, most participants did not explicitly express feelings of guilt; however, there were implicit mentions of it. Guilt was expressed in the form of fear; participants seemed to engage in fantasies surrounding the etiology of cancer and how it related to prevention. Furthermore, this view of causal etiology led them to fear that they would genetically pass cancer onto their children and this seemed to cause them great anguish. While some reflected that perhaps the way they had lived their lives had resulted in them getting cancer. This latent undertone of regret was seen when women tried to develop lifestyle changes to live a healthy lifestyle in order to reduce risk of recurrence or occurrence of cancer in their families. This was seen as attempts to bargain in order to prevent recurrence and live a better life.

> *Participant 5: "Everything in life happens for a reason and I got cancer for a reason... I see it as, how did I live my life that I did get cancer."*
> *Participant 3: "My hope is that by giving my children a healthy lifestyle and giving them a healthy outlook on life and a different perspective on life that they will be able to live life differently so that they don't get cancer. My hopes are that they grow up and they never get cancer and also hope that my husband will never get it. I want my family to be healthy and I want is to spend as much time together as possible."*

Physical suffering is exhibited through the experience of discomfort, changes in the body and side-effects of chemotherapy. Receiving treatment in the form of chemotherapy and/or radiation posed many hurdles for women. Chemotherapy was a drug regimen with many unpleasant side-effects; the treatment itself caused great damage to the body because its toxicity kills both

cancerous and non-cancerous cells. It seemed that receiving the diagnosis was the initial shock; however the most arduous times were those during which one was receiving treatment. Participants seemed to equate the harshness of treatment with death as opposed to diagnosis. Women outlined the main symptom profile as experiencing nausea; vomiting; hair loss; weight loss; fatigue; burns and depression. Some women (38%) made specific reference to their depression, while others (38%) made reference to symptoms of depression such as anhedonia, not wanting to partake in activities that they enjoyed, isolating themselves from others and general fatigue. Radiation was experienced as having less side-effects than chemotherapy, however it caused burns and resulted in fatigue as well as it consumed much of the women's time as it had to be administered daily. Most participants viewed treatment as a hindrance to their lives and thus resented it as they did not seem to have the internal resources to deal with this. Burns were reported to be terribly painful and due to repeated treatments, took a considerable time to heal. Participants experienced discomfort in their daily activities due to these side-effects. Additionally, participants stated that not being able to bath made them highly uncomfortable and resulted in them avoiding interpersonal interactions for fear of receiving negative comments regarding their hygiene.

Participant 5: "The after effects of the chemo were not nice: constipation and the nausea and the rotting of the teeth."
Participant 8: "Besides vomiting, I was feeling tired and there was a time when I'd go to the loo, I would close my nose because the urine it was smelling; even my skin, it was smelling like chemo. I used to wash my skin after three hours, I would wash myself and when I would go for another chemo, I would change the soap and the lotion because it was always smelling from me."

Chemotherapy was a challenge for all women in the study as it elicited feelings of anxiety, nervousness, depression, frustration, stress, and emotional and physical suffering. For some women, the experience of enduring chemotherapy was far more distressing than having cancer. This sense of suffering had severe implications for participants' sense of self and self-concept.

Participant 2: "*Whereas in actual fact all the things I went through was actually because of the treatment, it wasn't actually because I was feeling sick myself, it was kind of induced by all of these things.*"

At times, women stated that during treatment, they did not want to continue due to its harsh nature but either due to rationalisation that treatment would result in a cure or support from family and friends, they continued treatment. Some participants reacted to the chemotherapy with shortness of breath and heart palpitations. This seemed to induce feelings of dying and thus provoked greater anxiety and existential suffering in these women. Alternatively, in order to cope with the side-effects of the treatment, some women experienced treatment as having a positive effect on them. Some participants experienced that in order to be cured, one needed to endure pain; thus pain was the price one had to pay to continue to survive. They clung to the fact that the treatment was reducing their risk of death and thus assigned positive connotations to it.

Participant 7: "*But even if the chemo has side-effects, it takes out your hair, you feel nauseous, you feel sick, not like yourself but it definitely is a very good drug, though it does definitely kill your good and your bad cells, it should be administered to everyone who is diagnosed with cancer.*"

Breast cancer was perceived as a disease that affected primarily women and thus affected participants' views of self. Women tended to turn their thoughts inward upon receiving this cancer diagnosis. This introspection led them to question their self-esteem, self-perception and body image as well as their roles as mother, wife, sister and daughter. The breast was seen as beautiful and defined a woman; the invasion of the breast was seen as destructive to their femininity and seemingly affected the women's views of her body and of herself as well as her place in her community. Compounding factors that influenced views of self were those effects that treatment had on the women's skin, nails, hair and weight. Black women, in particular, were distressed over the prospect of losing their breast. This was evident in how they described having breast cancer. Black participants stated that breast symbolised their beauty and femininity as

well as their ability to nurture offspring in the African culture. Big, well-defined breasts were a sign of beauty and thus the prospect of invasion led them to question their views of themselves.

> *Participant 6: "For us, it's like our beauty because as you usually see when you're young you usually don't wear, if you're wearing this cultural attires, you don't have to wear anything around your breast because you have to show your breast because it's something that you're proud of. That is why it was hard for me, how am I going to go home, how am I going to cope; even in our society, in our culture, it's like you're not a complete woman, if you have one breast."*

Of more concern to the women in this study was the loss of their hair; most participants expressed shock and horror in losing their hair. It was evident that this was anticipated as 63% of the women had cut their hair in order to decrease their distress. They went onto state that when their hair fell out, it was still a shock but the amount of hair was comparatively less which made it less traumatic for them. Various coping mechanisms were employed including the use of wigs and isolation during times of physical and emotional distress. In addition to losing the hair on their head, they also lost their eyelashes, eyebrows and all body hair of which losing their eyelashes was most distressing. Women stated that they felt and looked terrible and that this affected their self-esteem and they experienced a loss of dignity.

There were a range of responses to the physical changes that the women encountered. Participant 8 recounted a deeply affirmative narrative of her experience of the side-effects of chemotherapy:

> *"When I lost my hair... I didn't even buy a wig or whatever. I live a normal life, like everyone else. Yes, I didn't buy any wig or wear some dooks. I just, I would make-up myself and treat myself and wear those big earrings. They tell me that I look attractive, even my doctor in the chemo he told me that I look beautiful. And you just have to walk tall, tell yourself that you are unique and special and you will get through it."*

Whereas Participant 4 experienced the side-effects chemotherapy as a rather negative experience:

"I would feel weak and not feel like talking and not feel like eating because I did not have any appetite, so that was depressing and I would lose weight and obviously the bones would show. And in the eyes, you know, you also lose your eyelashes, it was a nightmare to see myself in the mirror with no eyelashes. It changes your image and sometimes you would stay two weeks without food, not wanting to talk to anyone, it was a traumatic experience."

Tamoxifen was seen by these participants as a drug that caused weight gain and this was concerning to women as they felt that due to the lengthy period of time that they would be on the medication, that they would increase their weight substantially. These women seemed particularly sensitive about their weight and stated that they were previously fit or were dieting and achieving satisfactory results. This disruption caused them much suffering, in particular, the loss of who they once were. In addition to the loss of hair, increased weight loss and invasion of the breast, women reported having dry skin and discoloured nails which were all significant aspects of one's sense of self and perception of body image and body satisfaction. Vast changes seemed to decrease one's quality of life as they were not intrinsically satisfied and this coupled with the distress of receiving the diagnosis of a terminal illness may have resulted in an overall disheartened person.

4.1.2 Values in life

One's values in life are core aspects of their existential being. These views included views of self, of one's roles and responsibilities, hope and positivity, support and sense of control and normality. These values seemed to have been fundamentally changed and redefined due to the suffering and meaning-making efforts that participants had experienced. These changes in the individual were both positive and negative; positivity and hope seemed to have ameliorated the distress that participants felt in their physical and emotional experiences of having breast cancer.

4.1.2.1 Hope and Positivity

Hope and positivity seemed to permeate the response of participants and has been weaved in the various subthemes as such. These existential constructs seemed to mediate the fears and distress that participants felt in every aspect of their experience. Fear of living with illness or dying from illness fall within the realm of existentialism. Participants outlook on life are of significant importance when viewing their illness. Hope and positivity assist participant in seeing beyond the here-and-now of the terminal illness and provides optimism for the future.

> *Participant 4: "I'm a very positive person, when it comes to fear, fear is not my friend. When I've got something that is facing me, I've got to face it head on and I think about where I come from, where I am and where I'm going."*

The ending of chemotherapy and/or radiation was experienced as a joy and a relief by all women. It was seen as a victory; that one had conquered cancer. Most experienced the end of treatment as the beginning or continuation of their life; the ending treatment signified a 'cure' which was a cause for celebration. Small victories in treatment seemed to foster increased levels of hope and positivity that seemed to assist participants in continuing with treatment and 'defeating cancer.'

> *Participant 4: "It was great, I was counting down from the chemo and on the last day I arrived very early. It was my last and I said; now everything will be over because it's my last chemo I now will go to the nearest restaurant get the best buffet, because this is my last chemo... It was finished, in my mind that it cancer has gone."*
>
> *Participant 2: "I am so relieved it is over. I think because as I said my life is very busy and it's not like this filled a big gap in my life, it was a hindrance in every aspect my life from being in hospitals and doctors to having tests and having needles poked into me. I don't miss that at all!"*

Hope for the future all centred on recurrence and participants hoped that their cancer would not return and hoped to be well. They hoped their families, in particular their children, would not inherit their cancer. Participants hoped that their children would adopt the healthy lifestyle they had adopted in order to minimise their chance of diagnosis. Black participants hoped to prevent others, generally in their community, from receiving a cancer diagnosis by providing them with information and knowledge.

> *Participant 3: "My hope is that by giving my children a healthy lifestyle and giving them a healthy outlook on life and a different perspective on life that they will be able to live life differently so that they don't get cancer. My hopes are that they grow up and they never get cancer and also hope that my husband will never get it. I want my family to be healthy and I want is to spend as much time together as possible."*

4.1.2.2 Need for control and Normality

> *"I think that you're dealing with the physiological and psychological aspects of this experience then you've got to have the chemical that you can hardly survive, you can't function as a normal human being." (Participant 2)*

There seemed to be a struggle to maintain some sort of normality and control during one's treatment; these concepts seemed to be intertwined. Narratives prominently compartmentalised life from before with life now after the diagnosis. The predominant theme that seemed to underlie the concept of normality was the disruption of previous functioning in terms of one's capacities, roles and responsibilities. Prior to diagnosis, women engaged in fantasies of losing weight, studying further, gaining material possessions and advancing job opportunities. During their treatment, women seemed to cling to the notion of performing tasks and having things done in the way that they were previously done thus maintaining their roles. This strategy seemed to be in order to negate the effect of change and disruptions that had subsequently occurred in their lives and thus uncertainty in their lives would hopefully be diminished. In addition to the intrinsic grasping of normality, after commencing treatment, several outwardly noticeable

changes occurred in their bodies. These changes seemed to cause women great distress and thus the women aimed to retain some of their previous characteristics. This was most evident in the use of wigs to conceal hair loss that is commonly associated with chemotherapy. This was seen as an attempt to hold onto outward appearances of their femininity as well as to prevent further intrinsic distress from blatant public scrutiny.

> *Participant 1: "But the only people who saw me without my wig was my husband and my daughter; nobody else!... fortunately I got my wig before my hair fell out because like I said, I don't know what I would have done without it. And when someone would come over, they would say so-and-so is coming over, put on your wig. I think that helped me a lot because they did not saying anything because they know you are very sensitive about how I used to look."*

The need to control one's environment was used as a strategy to maintain a sense of continuity and as a distraction from illness. As all women that were employed commented, most used work and work performance in order to maintain a sense of control and thus experience a sense of normality. Some women stated that they would go for chemotherapy and then return to work shortly afterwards. They expressed the need not to deviate from their schedules and continued providing services to the best of their abilities as well as aimed to prove to others that even though they were sick, they were competent.

> *Participant 3: "I actually carried on working through my entire chemo, in fact, I would go to chemo and then straight afterwards, I would go back to work which I think actually helped, you know."*

Some women expressed distress due to not being able, at times, to perform to their previous level of competency, this was viewed as a source of distress from not being able to control what one once did and thus this initiated various levels of existential suffering in participants. Others (38%) felt that working hindering their progress in treatment and resigned from their jobs in order to focus on their health. This illustrated a tension, in these participants, between gaining

control and feeling overwhelmed or becoming disease-focussed. Participants that were more ambitious in terms of their career tried to maintain normality in this area whereas participants' who highly valued their role as mother, tried to maintain normality by sheltering their children from their illness by maintaining routines and performing tasks that were expected from them. These roles were mediated in terms of what participants valued or perceived as more important.

> *Participant 3: "You know, nobody ever really gave me a break... Around the third and the fourth one was when I was really sick and I think everybody gave me a day or two to lie in bed and be sick. And after that it was like we're waiting for dinner, please get going; it was that kind of thing. It's like I had their support but that they were also being quite harsh on me. But I don't actually feel like it's a bad thing, I'm actually happy that it was that way because it got me to say that I've had my two days and now I had to get on with life. And it actually helped, it actually helped a lot."*

Control was additionally exercised in the fostering of an environment that was conducive to positivity in the face of their adversity. Most of the Black participants (50%) stated that they had seen counsellors in order to come to terms with their diagnosis; other participants (38 %) stated that they had attended support groups and this assisted in the normalisation of having cancer. Women stated that knowing that there was a cancer-support community brought them great comfort and fostered social support and social cohesion. Another external source of support was that from medical staff and treatment centres, women stated that positive staff and the positive environment that they created fostered a sense of comfort and hope.

> *Participant 1: "And the doctors and nurses, they're actually very good. I must say, the chemo centre and the radiation centre, the doctors all of them, they were excellent. They were just there for you; they never moaned and carried on. They help you get through it and when you finish the chemo, it's like "well done, you've finished another one, well done!" And they all just help you. And that has helped so much and they've been positive, it really helps you be positive."*

4.1.2.3 Redefinition of values

Adapting to their 'new lives' involved participants accepting personal change and identifying how these changes influence personal fulfilment. This acceptance and re-definition of values were strongly associated with women finding meaning in their experience. The process meaning-making enabled them to move on and embrace the existential changes they had undergone.

Changes in lifestyle were also fundamental to these women's adjustment to cancer. Their previous thought processes were adjusted as to incorporate new information and views into the existing concepts in order to change women's views of the past and create a 'new, normal environment'. This resulted in these women adjusting and adapting to their new life circumstances. The most prominent change was that of a total change in lifestyle was reported in all facets of participants' lives. Women reported an intense need to look after their health. This was achieved by following healthy eating plans, exercising more frequently and most importantly, their focus on eliminating and decreasing stress in their environment. It seemed that it was of the utmost importance to change their lifestyles as to assist in the prevention of recurrence of cancer as well as to foster a healthy lifestyle for their families to act as preventative measures against a cancer diagnosis.

> *Participant 3: "It is important to be healthy, to live each day to the fullest, have fun in your life, be as close as possible to your children, be a good mother, be a good wife, it does change a lot of things, you know."*

A key element that emerged from the narratives was the redefinition one's global outlook on life. Women seemed to emerge with greater positivity and an integrated sense of meaning because of their existential self-reflection. It was evident that they changed the way in which they thought about life and the way they lived life. They seemed to engage in more intrinsically fulfilling activities such as hiking with their children or travelling when it was within their means.

Women expressed the need to live life to the fullest and experience every opportunity that came their way. For example:

> *Participant 2: "I feel like I must do everything in now... I think that it is important to experience all that there is to experience in life."*

Stress reduction was a core theme as most women attributed this as a possible cause for their diagnosis; this was evident in women's newly found self-acceptance and self-importance as well as their view of not taking things so seriously. Positivity seemed to permeate all aspects of one's outlook on life and meaning was integrated into one's self-concept.

> *Participant 1: "I also feel that I've changed because I don't just take life for granted any more. And I also think that certain things that happen and think, life is too short , just get over it or you don't stress about nonsense. You try and make the best of it and see good in everything, instead of moaning and complaining, just carry on."*

It seemed that the crux of making changes and redefining values was that before participants had cancer, life was not highly valued and was taken for granted. After diagnosis, participants realised that death is inevitable and that new meanings had to be created in order to value and fostered a new outlook on longevity. Changing ones habits, behaviours, beliefs and meanings was to show how life was currently valued.

4.2 Existential Meaning

The central and perpetuating theme was that of existential meaning; it linked all themes and was evident in all subthemes. Existential meaning was initiated by the fear of imminent death, this led women to channel all their energy into defeating cancer. In order to defeating cancer, women utilised th eir internal and external resources as well as their meaning-making processes. Women focussed on the here-and-now in order to create an opportunity to live their future. Cancer seemed to infringe on their lives and unsettle their existential concerns which led women to use

active strategies to defeat cancer by bolstering their sense of self, changing and reviewing their beliefs and lifestyles. Women seemed to reconnect with their religious and spiritual self and redefine their purpose in life.

4.2.1 Defeating Cancer

To defeat cancer, the development of effective coping skills was seen as important and was employed by all women. The underlying belief was that of hope and this bolstered the view that they would recover. Women reflected the need to fight to persevere for their families' sake and for themselves. This was achieved by the use of planning their treatment regimens, internalising their belief that treatment would be successful and being proactive in fighting their cancer. Participants stated that they had little, objective knowledge about cancer and thus cancer was feared. Therefore, gaining accurate information was a key source of coping as women stated that when they understood what had occurred in their body and how the treatment aimed to cure them; they were more hopeful and more invested in the process.

> *Participant 1: "It did help when she sat me down and she told me everything I needed to know, when she said it's ok, everyone reacts differently and you don't have to feel the way others say that they did. When I went to the radiation... She sat me down and she showed me a picture of this machine and they showed me what she was going to do to me... And that helped a lot because then you know because the thing is you don't know until someone tells you."*

Some women noted that it was a constructive strategy, at times, to utilise distractions such as work or caring for their family. This was important as they had something else to focus on so that they did not get lost in their cancer. Furthermore, looking back, the ending of treatment regimens were seen in a positive frame of mind as their cancer was considered to be defeated and a sense of normality could be re-established in their lives. Additionally, a unifying factor amongst women was the activation of the energy to confront and defeat cancer which was described as growth of their inner strength. The origin of this 'inner strength' varied amongst

women with some stating that it originated from their personality while others believed that it emerged from their religion and social support. For example;

> *Participant 3: "I wasn't a strong person like this before I was diagnosed... It's almost, I know people and they all think that I'm crazy but I often say to them that I'm often glad that I got cancer because this just made me a better person... I didn't know I had this inner strength... it's just I was diagnosed and all of a sudden I found the strength to deal with it"*

It was found that a key component in the fight against cancer was the quality of the support that women received during their treatment. This support came from family, friends, neighbours, colleagues and support facilities. Family support, in Black and White participants, was paramount to the successful coping with their diagnosis across all the participants. Women reported that during this time their strong familial bond was further developed. They stated that their families encouraged them through their difficult times and this gave them hope. It was vital for family and friends to accompany women to their treatment as this reduced their sense of isolation and hopelessness. Spouses and partners were especially important as they were reported to be supportive, motivational and seemed not to focus on their physical changes which assisted in the participants' assimilation of their new self.

> *Participant 6: "It helped me a lot that without them I wouldn't have survived… I would survive and be fine but emotionally, I would have scars and I wouldn't be as strong... gives you an inspiration that "Argh man, I'm still going to make it"; you will have a feeling that I still want to see these people around me so it pushes you to want to get healed."*

4.2.2 Quest for Meaning and Purpose

Meaning involved contemplating the reason for one receiving a breast cancer diagnosis as well as determining if there was a greater purpose behind the experience. During difficult times,

women generally intensely reflected on ‘the questions of: ‘why’; “why me”; “why now”. The intensity of the search for meaning varied, with some women viewing it as another issue they had to overcome and others viewing it as an opportunity for extensive personal change. This allowed women to engage in meaning-making and to incorporate this meaning into their sense of self. Women experienced as sense of ‘awakening’ after receiving a cancer diagnosis which caused them to re-assess and prioritise what was important in their lives. There was a profound sense of enlightenment and insight of one’s self. The overwhelming long-term response was that of acceptance and growth; acceptance of themselves in their entirety, the acceptance of their lives in its current state and the acceptance of living within their resources.

Religious and spiritual views amongst women varied; however all made reference to religion, spirituality or a combination of the two in their narratives. Participants primarily viewed religion as an external belief system from which to draw strength. Women seemed to find a sense of comfort in their respective faith and belief systems. Some (38%) stated that they were practising within their particular faith system, while others (38%) stated that they returned to practising their religion of choice which seemed to make the prospect of death and the difficulties of associated with chemotherapy easier to manage.

Meaning-making was expressed at great length in the narratives of religious women (63%). They reflected on how their faith gave them strength to persevere during difficult times Participants used religious materials in the form of books and music to find comfort as well as they engaged in the use of prayer and attending religious services. All religious participants stated that they felt that this experience had brought them closer to God and back to their path in life; this seemed to replace anxiety of death with hope and faith. Some stated that it was a reality check which assisted them in finding their true self while others reflected that it showed them their purpose in life. For example:

> *Participant 1: “You know without that I wouldn't have made it. You are a Christian, but you tend to forget these things. This brought me back again on the path and to the Lord; to know that he's doing all this for me. Sitting at the chemo, I would still pray and ask God to help me and he did. And without religion, I wouldn’t have made it.”*

Spirituality and religion were used interchangeably by some participants; however others made reference to spirituality in its pure sense. Spirituality was seen as a more holistic, personal existential concept which centred on a higher power, the interconnectedness of humanity and the essence of the soul. Stemming from this, participants seemed to be extracted meaning from interconnectedness amongst people, that they were entrusted to bring a positive message about breast cancer so that others learn from their experiences and live a better life. Furthermore, they stated that they wanted to improve their lives in order to attain autonomy and increase their overall quality of life.

> *Participant 8: "I am more spiritual because when you believe in something, it will happen. I tell myself I'm going to be okay and I am okay!"*

Spirituality was linked with the need for positive thinking and belief in oneself which resulted in transcendence and freed participants from their existential suffering. One major factor that assisted with this was having the opportunity to evaluate ones' life and views of death before existential crises occur. Meditation was a core aspect of meaning-making as it allowed women to reflect on their lives, their purpose and find energy, passion, desire or drive to find productive ways of moving forward.

> *Participant 5: "... three weeks before I actually found the lump, I did a spiritual course. Right from the start, it was like everything just fell into place and it was interesting that one of the questions that you had to meditate on was what you think of death. And I think actually having the opportunity to ask myself how I feel about death was the major factor that probably prepared me for the diagnosis."*

Modern life and values seemed to cloud participants' sense of true self. Success and wealth were all values that were previously valued by participants. Women stated that their professional success had always been their driving factor and this had resulted in them not living their lives to the fullest; they stated that now materialistic factors seemed to have less importance and the demands of everyday living had substantially decreased. Implicitly participants reflected that

their families had become more valuable and the need to spend as much time as possible with them outweighed their need for wealth, success and prestige. Therefore receiving a cancer diagnosis seemed to push them into re-evaluating their motives and had resulted in a more positive, balanced and intrinsically fulfilling life.

> *Participant 4:" I realised that having money and having material things, it's really not the real life. Real life is about spending time with people you love and doing good to other people."*

One woman recounted in a poignant narrative of how receiving her diagnosis led her to making one of the most important decisions in her life. She recounted being deeply troubled about working and not caring for her children. This led her to re-assess her roles as mother, wife and employee. She stated that she was happier and more content knowing that she was caring for her children and fulfilling her role as a mother and was able to achieve career success by running a business from home that she enjoyed. She stated that she felt holistically complete as she defined herself as a 'good mother' and a 'successful business woman'. A brief extract is used here:

> *Participant 3: "I wanted to be at home with my children and the work was keeping me away from it... I want to be with them, but I'm at work, it was an internal conflict. So, definitely, what came out of it was that I had to make a choice and it was being at work or spending time with my family and being there for my children... I think or asked, I said I need a sign and I got a big sign. And I think the whole meaning behind it was that I was forced to make a big decision which I made and then I made the right decision."*

Additionally, women seemed to review their previous altruistic tendencies; they seemed for find purpose in helping others. They stated that they had more interest in the general well-being of others and noted being more sympathetic and less selfish. This change in attitude was manifested in the way in which they predominantly interacted with other cancer participants; there was a great need to help and assist others with coming to terms and make meaning after

receiving their diagnosis. This seemed to emanate from their developed sense of insight, the lessons they learnt and the need for their experience not to be lost or wasted.

> *Participant 6: "Now it's different for me, if I see someone was sick, I have that sympathy for them I want to help, I want to do something, I go out of my way. Maybe even if the person doesn't have cancer it gives you a purpose of living. And why we came on this earth is to help each other."*
> *Participant 5: "I said that if I had to have cancer, there's a lesson to be taught and there's a lesson to be learnt. And if by being me, I can reach one person then it's worthwhile having cancer."*

Existential meaning seemed to result from the need to defeat cancer and live a more fulfilling life. Participants seemed to engage in various methods to understand their diagnosis and make meaning, the most prominent were the use of religion, spirituality and finding meaning in life.

4.3. Role of Culture

Culture seemed to be a mediating factor in participants' experience and meaning-making processes. All the Black participants in the study expressed their respective cultural values and perception of cancer; however this type of information was not elicited from the White participants in the study. The Black participants articulated great distress over their communities' lack of knowledge of cancer. They stated that this led to stigma around cancer and that they had to explain every aspect of their treatment to members of their communities, even if they had not properly internalised them yet. This seemed to cause distress in Black participants who at times wished to be isolated from their communities.

There were two aspects with regard to their communities perceptions and beliefs that upset participants. This was that the side-effects of chemotherapy were at times mistaken for symptoms of HIV and AIDS and that cancer was viewed as a curse or punishment from the ancestors. Participants stated that HIV and AIDS carried a far greater stigma than cancer and this led them to have to disclose their illness in order to clear up this misunderstanding. This

disclosure, if done pre-maturely was said to elicit distress and anxiety as well as foster isolation at times when social support was crucial. For example:

> *Participant 6: "When you are starting to go bald, they are like what's wrong with you, are you HIV-positive and all of this stuff, so you have to explain. This was difficult and you have to explain... so okay that's the worst part to explain yourself every time things happen, your friends change after you explain yourself and to other people that don't understand. When you're with them in the taxi, they say, "Oh Sissy, what's wrong with your nails; they are so Black, did you have a dye or something?" And then you have to explain, there is just the point where you feel that you can just use an aeroplane and have to talk to no one."*

In terms of traditional beliefs, Black participants stated that they were ridiculed and ostracised for following non-traditional treatment protocols. Participants articulated that community members did not believe that Black people could get cancer and attributed their symptoms to witchcraft or punishment from their ancestors. They stated that they felt like their community blamed them for having cancer. Women were encouraged to seek help from various traditional healers and faith worshippers who utilise traditional medicine rather that western treatment regimens.

> *Participant 7: "And they tell you really, no Black people would have cancer, it would be witchcraft and all that... they would tell me that "you should go to a sangoma and an inyanga to get a portion so you don't go the operation way, so don't even go there and do that... So the perception was that because I wasn't in mourning for 12 months for a widow that is why this thing happened to me... So, that's how they feel like this to your fault because you didn't behave well. So some people may be say for instance may be some people will still say that you had too many boyfriends, always there's always a misconception in the African community."*

In contrast, White participants did not express the need to answer questions or justify their diagnosis and symptoms to their friends, family or community members. Black participants

unpromptedly stated that when they were diagnosed, they called a family meeting in order to share their experience with their family and plan the route forward. Extended family, community members and neighbours were included in Black participant's experience of having cancer. When talking about family, White participants spoke primarily about the nuclear family. They stated that their support structure consisted of their husbands, children and close friends. They did not engage in narratives about cultural or societal perceptions of cancer, nor did they state that they were called to explain their diagnosis. Although, White participants made no mention of contacting their extended family, it cannot be assumed that they did not do this. However, it can be safely assumed here that extended family was not used as primary support structures of these women.

Results showed that South African women with breast cancer experienced a range of existential concerns such as meaning and purpose, connectedness, faith and belief, family and relationships, positivity, self esteem and sense of control. These themes represent the body of data collected. All women reported experiencing shock and uncertainty in relation to receiving a cancer diagnosis. Therefore it is assumed that the fundamental, core aspects of existentialism such as life and death as well as fear and hope are universal however other aspects such as meaning and purpose, view of self and family and relationships were mediated by extrinsic aspects of the women particularly culture and context. All women in this study engaged in meaning-making and utilised various mechanisms in their 'will to live'. This seemed to have been influenced by various levels of social support, as well as by their level of hope, positivity and redefinition of values.

Chapter 5: Discussion

The present study was both exploratory and inductive in nature. Existential concerns in the South African context were found not to be as developed as in other contexts and other components of the cancer experience. Nevertheless, empirical results from Europe and America were compared and contrasted in order to determine if the range of breast cancer experiences are universal. Several studies have sought to explore the experience of illness. Morse (1997) conducted a meta-synthesis of literature and stated that there were seldom clusters of qualitative studies on the same topic and thus when one aims to study within a particular study, one needs to work with similar research questions.

Landmark, Strandmark and Wahl (2001) conducted a study that investigated the meaning of existential issues in recently diagnosed Norwegian women with breast cancer. The Norwegian study elicited similar domains of experience to the current study in which participants in both studies expressed a strong will to live and defeat cancer. The key existential components of meaning-making were active mechanisms such as control, redefinition and re-evaluation of their pre-existing values. Although the current study aimed to explore similar concerns, the South African context varied somewhat from the Norwegian context in some important ways. Culture seemed to play an important mediating function in terms of existential concerns in this study, based in South Africa. There were differences noticed in the way in which Black and White participants made meaning and integrated their new sense of self. The reflections of White participants were similar to those of their Norwegian counterparts (Landmark, Strandmark & Wahl, 2001) whereas Black participants differed in terms of social support, cultural perceptions and values in life; however, in both instances meaning was made. Therefore it is assumed that the fundamental, core aspects of existentialism, such as life and death, as well as fear and hope were universal. However, other existential aspects such as meaning and purpose, view of self and family and relationships were mediated by other extrinsic aspects of the women particularly culture and context.

5.1 Existential Reflections

It was observed in this study that uncertainty, angst and fear, especially regarding remission and recurrence, elicited significant levels of distress. This distress was evidently experienced due to the facing mortality and no longer possessing the ability to deny the belief that 'it would not happen to them.' Uncertainty was experienced at every stage of cancer; Landmark, Strandmark & Wahl (2001) provided support for this when they stated that women experienced distress as to what they must, should and wish to do when they become threatened by breast cancer. It was evident that receiving a cancer diagnosis elicited feelings of disbelief and denial and shock. This was understood in terms of theories of grief where Kübler-Ross (1969) stated that the initial period following diagnosis was marred by denial in order to allow patients to access resources that enable them to cope with their diagnosis.

As this period of shock and disbelief subsided, the loss of temporality seemed to elicit feelings of existential concern. The loss of temporality can be understood in this context as the loss of future perspectives and possibilities which seemed to initiate feelings of guilt and remorse which was understood as not a good life (Pascal & Endacott, 2010) and being responsible for receiving their diagnosis (Krombein & de Villiers, 2006). Furthermore, Blinderman and Cherny's study (2005) concurred with these results and found that feelings of guilt and remorse may have resulted in many participants expressing a desire to live and fight cancer. Underlying feelings of guilt and remorse was the need to bargain; these themes were expressed latently as the need to change ones' lifestyle and help others who were newly diagnosed with cancer come to terms with their diagnosis. These findings were congruent with Kübler-Ross's stage of bargaining and were seen as negotiating and entering into a covenant with a higher power in order to live a longer life. Kübler-Ross (1969) stated that these pleas and conditions were not often materialised however, in this study all participants were currently attempting to fulfil their 'bargains' thus fulfilling their covenant and hoping for remission. From these pleas or bargains, significant lifestyle changes seemed to emerge. For example, participants engaged in general health improvement in a bid to prevent cancer from recurring or occurring in their families. These changes included the

adoption of new healthy behaviours such as exercise, eating a healthier diet, controlling stress and engaging in religious and spiritual practices.

In this study, treatment seemed to be feared more than having the diagnosis of cancer itself and thus the process of treatment seemed to result in significant levels of existential suffering. Moreover, existential suffering was seen as a result of feeling of angst, distress, guilt, fear, pain and uncertainty. This finding was supported by studies by Arman and Rehnsfeldt (2003); Landmark, Standmark and Wahl (2001) and Pascal and Endacott (2010). Greater levels of existential suffering further added to the physical suffering during treatment. Emotional and physical suffering seemed to result in a decrease in quality of life which was evident when participants engaged temporarily in periods of isolation and depression. Rustøen, Cooper and Miaskowski (2010) stated that poorer health status and lower levels of hope led to higher levels of psychological distress. Although the results of this study agree with those results pertaining to hope posed by Rustøen, Cooper and Miaskowski (2010), it differs in that women with more progressive tumours, at the end of treatment exhibited higher levels of hope and were more psychologically well-adjusted. However, within this study, this was linked with high levels of hope and sense of control. It is believed that South African women with more progressive tumours actively engaged in and utilised all their resources the fight against cancer in order to survive.

Participants' sense of self was affected by various changes that occurred as this redefinition was necessary for meaning-making to occur. Physical appearance seemed to be inextricably linked to sense of self and body image as these aspects are essential to what characterised 'a woman'. However, these views were disrupted after surgery and treatment and thus prompted a re-conceptualisation of femininity. This had a significant effect on self-esteem, self-perception and sense of self. Furthermore sense of self was not merely composed of femininity; roles and responsibilities as well as drives and beliefs were additional components of sense of self. Sharpe and Curran (2006) reported that women reappraise existing beliefs, rules, values and roles that had previously given life meaning order to guide coping behaviour. This was manifested in this study as a re-evaluation of values in life and this changed focus assisted in restoring emotional equilibrium that was disrupted by women's existential crisis.

This study delineated how suffering was managed by the need for and use of control. Lally (2010) added that having control of life was an integral component of self-concept. This was evident, in this study, as various methods were employed to retain or regain control of internal thoughts and immediate external environment, all of which were mediated by the meaning that was ascribed to the experience of suffering. O'Connor, Wicker and Germino (1990) stated that roles and responsibilities of patients were generally related to their purpose in the world and thus loss of roles seemed to diminish patients' perceived purpose in their world. A need to control those roles that were most important to self-concept such as being a 'good mother'; 'efficient employee' or 'successful executive' was evident in this study. In addition, participants controlled their environment as to how they were viewed by others and the degree that they would allow the diagnosis to change their lives, thus the reduction of discord within one's self lessened distress and anguish in participants was noticed. Furthermore, social support resources were actively sourced in order to bolster sense of self, views of hope and positivity as well as to assist in meaning-making.

Earlier, hope was described as an essential component of meaning-making (O'Connor, Wicker & Germino, 1990) and seemed to exhibit a mediating relationship between psychological distress and life satisfaction (Ferrell et al., 1998; Rustøen, Cooper & Miaskowski, 2010). It was evident, it this study that hope and positivity replaced existential distress, as hope was seen as inseparably joined with future prospects. Hope for the future was derived from positivity, religion, faith and meaning were emphasised. This was emphasised when women finished their treatment as they felt that they had defeated cancer and were now cured. This hope that treatment would be successful assisted them in persevering through the difficult treatment and resulted in remission. According to Fromm (1968 as cited in Landmark, Strandmark & Wahl, 2001) having hope is imperative to bringing about change and in making life more survivable. Hope is neither a passive process, nor an unrealistic expectation of something that cannot occur. Fromm further added that there is no purpose of hoping for something that already exists or for something that cannot exist; hope only exists where hopelessness threatens to conquer. Thus hope, within the confines of this study, was viewed as a strategy, rather than an outcome, that aided coping with the psychological distress associated with cancer.

5.2 Existential Meaning

Previous studies by Kernan and Lepore (2009); Tomich and Helgeson (2002); Westman, Bergenmar and Anderson (2006) questioned whether the search for meaning or meaning-making is necessary for adjustment and acceptance of one's illness. Westman, Bergenmar & Anderson (2006) reported that not all of the participants found that their cancer diagnosis pushed them to search for meaning in life. Furthermore, Kernan and Lepore (2009) found no significant concurrent or longitudinal associations between searching for meaning and made meaning of having cancer. In their view, this suggested that searching for meaning may be futile in some women and may result in a distressing psychological state if meaning is not found. Significantly, this study found that all participants engaged in an intense search for meaning and personal quest for personal understanding and seemed to find meaning and transcendence in suffering. Two sources were found to assist in search for meaning: 'religion and spirituality' and 'purpose and values in life'. In this study, religion and spirituality were confirmed as core concepts to the process of meaning-making and coping. However, these two sources seemed to be inextricably linked in that meaning was achieved once a change in values and purpose in life were re-evaluated. Most participants attributed meaning in their life to raising a family. This was of significance as women felt that they had overlooked their families in order to focus on the busy pace of life. Thus having cancer had provided them on opportunity to live an intrinsically fulfilling life. This was complimented by religious participants believing that meaning came from God as well as from their family and spiritual participants expressed personal and spiritual beliefs as defining meaning in their lives.

Morse (1997) delineated five stages in an illness experience of which suffering, meaning-making and transcendence were the underlying themes. All of these themes were evident in the present study as well as studies by Arman and Rehnsfeldt (2003); Lally (2010); Landmark, Standmark and Wahl (2001) and O'Connor, Wicker and Germino (1990). Themes of meaning-making, suffering and transcendence have been written about at length by Frankl (1970; 1978; 1997;

2006) which served as a theoretical basis for this study. Thus an application to this theory is necessary. Suffering has been delineated through this chapter as the loss of previous life functioning, pain, fear and disintegration of sense of self. This suffering seemed to elicit the need to break free from the existential vacuum and led to the 'will' to find meaning. Thus women reported noticing the absurdity of modern life, which prompted them to redefine their values which initiated their search for meaning. The search for meaning concluded when religion, spirituality and purpose in life were utilised in order to re-evaluate and redefine purpose in life. Therefore in this study women sought and found meaning which resulted in transcendence above cancer. Thus suffering, in this study, was therefore seen as a transitional stage that usually invoked an existential re-evaluation and redefinition of one's outlook on life in terms of self, other and the world.

According to Sharpe and Curran (2006), changes in beliefs are fundamental for meaning-making. These notions were also inherent in Beck's cognitive theory (Beck, 1989; Beck, 2005) as he defined that the way in which one finds purpose and meaning as well as views emotional suffering, is as a result of the way in which a person construes their world. Thus contextual and cultural beliefs are essential when understanding meaning-making. Lally (2010) further added that the breast cancer diagnosis initiated a threat against the pre-existing views that women held of their self and their world. Receiving a cancer diagnosis seemed to unsettle views and attitudes towards life; this finding concurred with O'Connor, Wicker and Germino's study (1990) that stated that an attitudinal change towards life was a result of patients' cancer diagnosis. In this study, it was evident that the pre-cancer meaning of life was tested. This resulted in new meanings and values being created with led to the changing of belief and meaning systems in order to show how ones' 'new life' was valued. Halldórsdótti and Hamrin (1996) stated that the lived experience of having cancer seemed to involve many existential changes that were mostly a burden on the individual. However, this study opposed this finding as women emphasised appreciation and value of the changes that they had undergone in light of their diagnosis. Thus treatment was seen as a burden but cancer was seen as transcending and was seen by most as a 'growth' or 'learning' experience. While illness is typically viewed as destructive; illness was reconstructed in order to cope with and achieve meaning. This redefinition of cancer as positive seemed to foster hope, positivity, social cohesion and faith which possibly led to transcendence

over their suffering. Thus having cancer and suffering was viewed as a positive experience by most participants. There seemed to be cyclical interaction between hope, positivity, social support and faith as they were seen as both mediators and were mediated.

Paradoxically, the redefinition of values and purpose led to value being attributed to the 'small things in life' such as seeing their children grow up, helping them with their homework and having special relationships with others. This resulted in a greater meaning in life, positivity and hope as well as the need to live life to the fullest. Arman and Rehnsfeldt (2003) stated that reordering priorities and learning to "say no" were fundamental components in women's decisions to achieve and retain their own health. The result of transcending suffering was a more integrated sense of self where self acceptance and boundaries were more prominent. This notion was supported by Allen, Savadatti and Levy (2009); Lally (2010); Landmark, Strandmark and Wahl (2001) and O'Connor, Wicker & Germino (1990). In addition, women appeared to surround themselves with people who brought positivity and love into their lives (Halldórsdótti & Hamrin, 1996; Sammarco, 2001; Westman, Bergenmar & Anderson, 2006) and thus autonomy, sense of self and meaning was re-established which were lost due to the disintegration of self that occurred at diagnosis.

Religious and spiritual knowledge assisted with fostering hope and assigning meaning. This was further emphasised by various authors (Arman & Rehnsfeldt, 2003; Blinderman & Cherney, 2010; Ferrell et al., 1998; Logan, Hackbusch-Pinto & Grasse, 2006; Taylor, 2006). In this study, religion was seen as source from which to draw strength in order to make the prospect of death easier to manage, thus decreasing death anxiety. Religion and spirituality were often used interchangeably; when used by religious women, it reflected interconnectivity amongst souls and a belief in healing whereas women who defined themselves as 'spiritual' described spirituality as an interconnectedness between individuals and the belief in one's self. Similarly, a study conducted on religious participants established that the concept of God was more representative of a person's spirituality than their religiosity (O'Connor, Wicker & Germino, 1990). This has implications for this study, as participants were linked by human connectedness and belief of helping others. Taylor (2006) observed the most prevalent spiritual needs as finding meaning, giving love to others, keeping a positive perspective and relating to God. Furthermore, engaging

in spiritual practise and endured positive spiritual changes assisted in meaning-making processes of having breast cancer. Ferrell et al. (1998) characterised spiritual well being as having purpose for living, increased life meaning, hopefulness, positive spiritual changes and valuing the importance of spiritual practice. Thus faith, in God, man or spirit, seemed to help participants cope with their diagnosis by drawing on support from religion, restoring faith and fostering hope of recovery. Therefore, meaning-making seems to be a spiritual and psychosocial process.

Meaning-making and coping were the most important tools utilised in order to come to terms with the diagnosis and overcome treatment successfully. Meaning-making was a process that reflected the need to find reasons for the diagnosis as well as determining a greater purpose in life in order to re-integrate ones' disintegrated sense of self. Receiving the diagnosis seemed to lead women into make important decisions regarding their family and resources as they were made aware that life was finite. This newfound purpose and meaning, as well as, the opportunity to re-assess and re-evaluate their morals, values and relationships led to greater insight which resulted in higher levels of positivity, and a more balanced and intrinsically fulfilling life. In addition, meaning-making was also attributed to the participant's need to help others. Some women also communicated their heightened altruistic sense of wanting to 'give back' or help others, out of a sense of gratitude for the help and support they had received during their treatment as well as the need not to waste their experience; these sentiments were echoed by Henouch and Danielson (2009). This study seemed to integrate the finding of previous studies (Allen, Savadatti & Levy, 2009; Arman & Rehnsfeldt, 2003; Blinderman & Cherney, 2010; Ferrell et al., 1998; Logan, Hackbusch-Pinto & Grasse, 2006; Lally, 2010; Landmark, Strandmark & Wahl, 2001; O'Connor, Wicker & Germino, 1990; Taylor, 2006) into a holistic account of existential experience of breast cancer while qualifying differences with these concerns within various contexts and cultures.

5.3 Role of Culture

Culture was indicated in this study as an important theme in the existential process. Westman, Bergenmar and Anderson (2006) acknowledged that knowledge and metaphysical beliefs about

cancer have a significant impact on the patient's views and thus their ability to cope with the disease. Therefore, the importance that women placed on culture seemed to mediate meaning-making by placing importance on life values, beliefs and support structures has been re-affirmed. Thus, it is important to ascertain women's definitions of culture and how they define themselves in order to understand South African reflections of breast cancer. It would be inaccurate to assume that due to racial affiliations that participants subscribe to particular cultural or religious beliefs. This study was useful as it placed the South African experience of breast cancer into a cultural context; it showed that a country with such diversity, experienced breast cancer differently while qualifying that existential concerns are universal. There were marked differences in how Black and White participants made meaning of cancer; specifically Black participants emphasised the role of their culture in their narratives as well as placed emphasis on different values such as body image, nurturance and sense of community.

The differences in existential experiences were viewed in term of individualistic and collectivistic cultures rather than racial delineations. Black participants seemed to fall within collectivistic cultures and White participants seemed to fall within individualistic cultures. This distinction was determined by the degree that participants spoke about culture, religion and how they described their social support structures. In collectivistic cultures, where interaction is frequent, group perceptions seemed to influence individual perception as well as had a greater impact on participants (Sparks & Villagran, 2009). In individualistic cultures, group interaction seemed infrequent and women surround themselves with close friends and immediate family (Sparks & Villagran, 2009). Thus in this study, Black participants were frequently effected by their cultural views of cancer whereas White participants made no explicit mention of this.

Experience and perceptions seemed to be influenced by others. Collectivistic cultures seemed to share their experience with friends, family and neighbours. Pillay (1996) found that views of cancer in Black communities were influenced by traditional African beliefs. He stated that African religions believe that when illness occurs, the physical and the spiritual dimensions require treatment before health can be achieved (Pillay, 1996). The Black participant group in this study, did not follow African religions in their entirety and seemed to display moderate levels of acculturation to Western values. However, when participants chose the western

treatment of chemotherapy and radiation, they stated that their communities ostracised them for following this treatment regimen due to the belief they had been cursed or punished by the ancestors and should have utilised traditional healing and medicine to make reparation. This was significant in that even though participants did not view their illness within a traditional framework, they experienced psychological distress. This distress seemed to impede psychological adjustment and assimilation of physical changes into sense of self and thus may have resulted in further existential suffering. In individualistic cultures, cancer was seen as a challenge imposed by a higher power however due to the scientification of western society (Higgs & Smith, 2006), western medication was often the route of choice. These participants did not need to disclose or explain themselves as cancer was a common illness and misconceptions of etiology and treatment were low.

The results of this study revealed that White women experience similar experiences, behaviours and thoughts as their western counterparts whereas Black women experienced breast cancer differently. Various components of existential concerns held varying levels of importance for the different racial groups. Black participants seemed to hold traditional beliefs about their breasts and body images. Within traditional African culture, the breast has historically been more overtly a symbol of nurturance and maternity (Schlebusch & van Oers, 1999). White participants did not explicitly mention the breast as representing a loss of nurturance or femininity however; this may be due to the Western construction of the breast being more covert and eroticised (Schlebusch & van Oers, 1999). The attribution of meaning of all participants to their diagnosis varied. Black participants explicitly stated that increasing awareness and knowledge of breast cancer within their communities were part of their meaning-making processes whereas half of the White participant group stated that their purpose was to get a positive message of breast cancer across to other breast cancer patients. This difference may be accounted for by the integral nature of the community into the lives of these Black participants (Pillay, 2001; Pillay, 2002) and the adoption of sense of community by White participants.

5.4 Conclusion

At the core of existentialism is the struggle to make meaning of our lives. From this study, it is evident that South African women engage in meaning-making activities and successfully negotiate these in order to achieve meaning and adjustment to having breast cancer. Existential domains (meaning and purpose; connectedness; faith and belief; family and relationships; positivity; self esteem and sense of control) were consistent in Black and White participants. However, there is a difference in the value attached to these various existential concerns that was expressed as culturally different. The most pivotal concerns were the needs to construct meaning and purpose around family and relationships. This study sought to explore the existential concerns of South African women with breast cancer and how they made-meaning of their ensuing life circumstances. Meaning was specifically attributed to women's roles as mothers and living a simpler, more satisfying life. This was linked to religion and spirituality with the essence of meaning being attributed to interconnectedness between mankind and a higher power that willed women to live a better life and be more connected with others. Thus the purpose and meaning of life was simplified and resulted in greater levels of inter-dependency and connectedness with others, autonomy and an integrated sense of self.

Culture played a critical role in determining how participants viewed and subsequently dealt with their illness. However, cultural views were limited to the race, gender and religion of participants and thus represented Black and White South Africans from predominantly of Christian faith. However, what was evident in this study was that Black participants subscribed to traditional belief systems (excluding religion) while White participants subscribed to Western belief systems. These affected participants' views of self with the breast being more emphasised in Black participants and utilising community resources in the bid to regain their health. White participants experienced drastic role changes and primarily gained strength from their immediate family and close friends.

This study provides support for Kübler-Ross's (1969) stage of bargaining as all participants engaged in bargaining activities in order to increase longevity and eventually make-meaning of

their diagnosis. Frankl's theory (1970; 1997) provided a strong theoretical framework of this study. The author postulates that South African women experience suffering that led to the redefinition of values in life in order for meaning to be adjusted. This was seen as transcending and resulted in a more intrinsically satisfying life. Thus, the will to live is fundamental to these South African women and thus the existential experience of cancer is universal.

5.4.1 Limitations

This study contained various avenues for improvement. The sample comprised of eight participants; given the small sample size, this study has limited generalisability. This cohort had the benefit of a support group where existential issues may have been discussed. This may have led to some saturation as not many respondents engaged with the depth of these issues. As participants may have extensively engaged with meaning-making and adjustment due to the psychological services they utilised during treatment, these participants were not representative of the total population of South African women with breast cancer who completed their treatment in the last year. Furthermore, as participants were subjected to a single interview; this may not have been representative of the range of existential concerns they experienced. From a quantitative standpoint, the use of qualitative research might be considered as lacking objectivity and measurable results which may decrease its reliability and validity in terms of methodology (Ashworth, 2006; Snape & Spencer, 2003). However, the goal of this study was not to generalise results beyond this study but rather to produce rich descriptions of the subjective experiences of these participants.

As Thematic Content Analysis looked at the superficial and latent content, this was a two-fold process of discovering the meanings embedded within the participants' narratives. The researcher strived to, as unobtrusively as possible, understand the participants' views and asked critical questions about the participants narratives, while being aware that there is no absolute relationship between what participants express and what they have experienced (Lyons, 2007). However, no qualitative study is analysed without the lens of the researcher (Lyons, 2007). Thus it must be acknowledged that the researcher's pre-existing knowledge and conceptions of breast cancer may have been actively implicated in the analytic process as the researcher tried to describe and account

for the participants' existential experiences of breast cancer. Furthermore, the researcher's own existential beliefs and meanings may have influenced the way in which she analysed the data.

5.4.2 Implications for Future Research

Although generalisability is not a primary aim of qualitative research, it is important for research to contribute to its field and generate possibilities for new understandings of the subject matter in different contexts. The exploration of existential concerns of breast cancer in South Africa is a promising field; thus, this research hopes to contribute to the existing knowledge base in South Africa. It is hoped that the results from this study may be explored and expanded upon by other researchers in the endeavour to further scientific knowledge in this young area of research, especially in the South African context.

This study focussed on women who had access to cancer support facilities. This is indicative of women being of a particular resource base and more studies should be conducted on women from various rungs of society. Therefore, there is a need for the expansion for participant criteria to include women from various cultural, religious and racial affiliations in order to accurately reflect the South African population. This will assist in further identifying the aspects of culture that affect existential concerns. The narratives of this study were rich with coping and defence mechanisms employed by participants to accept and make meaning of their experience. As this was not within the scope of this study, further research into the coping strategies employed by South African women with breast cancer and how these processes are meditated by culture and other personal variables is suggested.

A longitudinal study into the experience of women during the various stages of cancer, diagnosis, treatment and termination of treatment, would be useful in order to establish their dominant and rudimentary existential concerns as well as how these concerns develop and transform over time. This may provide much insight into the course that women follow and may be essential for developing interventions suited to each stage of their experience. In addition, some participants stated that there was a lack of accurate knowledge about breast cancer therefore there seems to be a

need for comprehensive interventions to address stigma and education associated with breast cancer in order to decrease psychological distress in these under-resourced communities.

This research, further illustrated some ways in which theories of suffering and meaning– in this case, how Frankl's (1970) theory differs from real experiences of meaning-making in this context of being a South Africa woman with breast cancer. However, research in other contexts may reveal differing results. The similarities and differences of the theory to real experiences have gained limited attention in recent literature, and the extension of research into the experiences of women with breast cancer in other contexts is advocated. It has also been found that religion and spirituality as well as culture was highly salient concepts for a significant proportion of South Africans, and its effects on the making meaning of existential processes deserve to be explored in more depth.

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Appendix A: Ethical Clearance Certificate

Appendix B: Information Cover Sheet

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559

Dear Participant

Good day, my name is Louise Moodley; I am a Psychology student at the University of Witwatersrand. I am conducting research for the purposes of obtaining a Masters Degree in Psychology. The aim of my research project is to explore how you experienced having breast cancer; how having breast cancer has affected your life; how you have moved on from having breast cancer to now no longer needing treatment as well as what your hopes and fantasies for the future are?

I would like to invite you to participate in my study. Participation in this research will entail being interviewed by myself, at a time and place that is convenient for you. The interview will last approximately 1 hour. With your permission this interview will be audio- recorded. Participation is voluntary, and no person will be disadvantaged in any way for choosing not to participate in the study. All of your responses will be kept confidential, and no information that could identify you would be included in the research report. The interview material (tapes and transcripts) will not be seen or read by any person other than myself and my supervisor. You may refuse to answer any questions you would prefer not to, and you may choose to withdraw from the study at any point.

This research will contribute towards creating greater awareness and discussion around breast cancer and the experiences of breast cancer survivors in South Africa. On completion of the study, you will receive a webpage address which will provide you with a summary of the findings as well it will serve as a forum to answer any questions that you may have about the findings. This information will be available on 30 January 2011.

Should you feel any distress after the interview and require any counselling, please contact me and I will refer you to a professional who can help you at no charge to yourself. Furthermore, I would like to include the number of a support group for women with breast cancer, their name is Bosom Buddies 0860 buddie / 0860 283343.If you choose to participate, please contact me telephonically on (072) 437-5198 or you can email me at Louise.Moodley@students.wits.ac.za and I will contact you personally. If you have any queries feel free to contact me.

Many thanks

___________________________	________________________________
Louise Moodley	Dr. Vinitha Jithoo
Researcher	Research Supervisor

072-437-5198 011-717-4523

Appendix C: Interview Consent Form

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559

I, ____ consent to being interviewed by Miss Louise Moodley for her study on the existential reflections of South African breast cancer patients.

I understand that:

- Participation in this interview is voluntary.
- I may refuse to answer any questions I would prefer not to.
- I may withdraw from the study at any time.
- Since I have had face-to-face contact with the researcher that my anonymity cannot be ensured however no information that may identify me will be included in the research report, and my responses will remain confidential.
- The researcher will use a code to identify me in the transcripts as well as the research report.

Signed: ____

Date: ____

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559

Appendix D: Audio-recording Consent

I, ____ consent to my interview with Miss Louise Moodley, for her study on the existential reflections of South African breast cancer patients, being recorded. I understand that:

- The tapes and transcripts will not be seen or heard by any person other than the researcher and her supervisor.
- The researcher will transcribe the tapes into transcripts.
- The tapes will be destroyed after the research has been ratified.
- All transcripts will be kept for the period of five (5) years and will then be destroyed.
- No identifying information will be used in the transcripts or the research report.

Signed: ______________________________________

Date: ______________________________________

Appendix E: Consent for the use of direct quotations

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, WITS, 2050
Tel: (011) 717 4500 Fax: (011) 717 4559

I, ____ consent to my interview with Miss Louise Moodley, for her study on the existential reflections of South African breast cancer patients, being used in the research report.

I understand that:

- My words may be directly quoted in the research report.
- My words in no way will reflect my identity.
- My quotations will not be taken out of context or modified in any way.

Signed: ____

Date: ____

Appendix F: Interview Schedule

Good day, thank you for taking the time out to meet with me. How are you? I would like to ask you a few questions just so that I can get to know you a little better. I would like to remind you that you may refuse to answer any questions you would prefer not to, and you may choose to withdraw from the study at any point. May I proceed? (Ask demographic questions in a conversational manner in order to build rapport with the participant)

<u>Demographic Information:</u>

Age: ______________________________________
Cultural or Religious Affiliation (if any): ______________________________________
Marital Status: ______________________________________
Employment Status: ______________________________________
Stage of tumour on initial diagnosis: ______________________________________
Duration since last treatment: ______________________________________

<u>Primary Question:</u>

"Could you please, in as much detail as possible, tell me about your experience of having breast cancer?"

<u>Probes</u>

- "In what ways has breast cancer affected your life?"
- 'During your cancer treatment, what would you say gave you meaning?"
- "In facing the challenges, what helped you persevere during your treatment?"
- "What are your hopes and fantasies for the future?"
- "How have you experienced no longer requiring treatment?"
- Non-specific probes: 'tell me more'; 'how did that affect you'; 'how was that for you?'

Thank you very much for participating in my study. Is there anything you would like to discuss further with me? Have a good day.